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Disability Rights and Independent Living Movement Oral History Series

BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY
VOLUME V

Jacquelyn Brand

PARENT ADVOCATE FOR INDEPENDENT LIVING, FOUNDER
OF THE DISABLED CHILDREN'S COMPUTER GROUP AND
THE ALLIANCE FOR TECHNOLOGY ACCESS

Doreen Pam Steneberg

PARENT ADVOCATE FOR EDUCATIONAL RIGHTS FOR
CHILDREN WITH DISABILITIES

Interviews Conducted by
Denise Sherer Jacobson
and Julie Drucker
1998-1999

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SERIES INTRODUCTION--The Disability Rights and Independent Living Movement, by Simi Linton

When I was asked to write the introduction to the Bancroft Library's oral histories on the disability rights movement in Berkeley, it reminded me of the summer of 1975, when I left New York City and headed out to Berkeley, California. For Berkeley was the place to be I told my friends, filled with hippies and free love. I would spend the summer, take courses at the university. I had been disabled just a few years and this was my first trip on my own, away from the tight circle of family and friends I had relied on in those early years.

Someone had told me that Berkeley was a center of disability activism, but I didn't tally that in my list of reasons to go there. I was a naive young woman in my twenties, and still new to disability. I "managed" my disability by keeping its profile low, and its needs in check. I use a wheelchair, and did then, and decided I would need to call the disabled students' office at the university to get help finding an accessible apartment near the campus, but also decided this would be the only concession I would make to my disabled state. I was fine, I told myself and my family, and by that I meant I could go anywhere, I could do everything. Disability would not bog me down and it would not mark me.

While bold on the outside, I harbored the deep fear that I might fail in my ability to keep disability in its place, that it would come crashing in around me and swallow me up. I, therefore, was completely unprepared for the headlong leap I made that summer toward disability, toward the people and the territory that I had shunned. I never imagined that I would move toward disability with interest and gusto. It didn't happen all at once in that brief summer, but I call that time in Berkeley my coming out.

I had arrived in a place where disability seemed more ordinary than it was where I had come from, where accommodations were apparent, where the curbcuts on every corner made it possible for me to go to the supermarket, to the bookstore and up to campus without having to stop someone at each corner, explain to them how to tilt my wheelchair back, take it down the curb, and lift it back up on the other side. Although Berkeley may not have had significantly more disabled people than other places, it seemed to. Maybe it was because I was out on the streets more than I was in New York. I saw people acting out the daily routines of life--going to the supermarket, school or their jobs--using wheelchairs or crutches, brandishing white canes, using sign language and all of the other indicators of membership.

And life started to become easier and more flavorful, not by avoiding disability but by living with it in a different way. The lure of the other disabled people I saw was great, and I learned that it was those people, most I never got to meet, who were responsible for the curb cuts, accessible bathrooms, the independent living center where I went for help, and the disabled students office that had found an apartment for me. I had never seen any place where disabled people were in charge and it thrilled me and made me optimistic about my life in a way that no other experience could.

I learned back then that it was not some benevolent church group that carved out those curb cuts, or a member of the town council trying to get votes who mandated accessible facilities, they were due to the deliberate actions and painstaking labor of members of the disability community who fought for the changes that were made. Their work set the stage for the ongoing struggle for rights and liberties that has engaged a nation of activists. Today, while discrimination remains a constant in disabled people's lives, the right to an accessible environment, to housing, employment, and transportation is governed by laws that are increasingly exerting influence on those who discriminate. Further, the idea of integration, in education, in public accommodations and in transportation, pervades the informed discourse on disability rights and is supported, again, by legislation that mandates desegregating society.

The Bancroft Library's Regional Oral History Office project, "The Disability Rights and Independent Living Movement: The Formative Years in Berkeley, California, 1960s-1980s," exposes the brick and mortar of these victories. Present in the narratives are major players and significant events, as well as the vital auxiliary figures and contributing influences that form the connective tissue of the Berkeley portion of these movements. The histories also reveal the dilemmas and roadblocks that halted progress and interfered with the integrated and equitable society that the framers of this political agenda envisioned.

It is a critical time to look closely at the progress that has occurred, and to study the impairments and deficits that remain in our not yet fully integrated and equitable society. Researchers, activists and those who write policy need, of course, to examine the present moment, and evaluate the necessary steps to take to move forward. Yet, just as important, is an examination of what led us here. How are present problems connected to past struggles? How do ideas that we act on today, relate to those formulated in past eras?

The oral history project provides detailed answers to those research questions. The material they have assembled will be of value to researchers, artists of all kinds, activists and policy makers. This endeavor is made possible now by opportunities afforded by the present moment that were not readily available before. The early activities and ideas have had the opportunity to grow and take root. There has been

time to evaluate their impact and to see the shifts in ideas, policy, and human interactions spurred by what at first glance might seem to be a random set of activities undertaken in reaction to specific concrete problems.

In addition, there have been a number of developments over the last three decades that have created both the need and the impetus for this work. I've grouped these into four sections that outline some of the cultural, scholarly and political activity that informs this work.

The Social Construction of Disability and the Significance of Community

What I witnessed in the summer of 1975 when I came to Berkeley from New York was that disability could mean something different just by moving to a new location. I wouldn't learn the term "social construction" for another fifteen years, but I did learn through direct experience that disability is not fixed. I also learned that the disability community is a powerful and meaningful entity.

Fundamental to the Regional Oral History Office project is an understanding of the social construction of disability. The efforts begun in the sixties by the people interviewed here to reframe disability as a social designation and to conceptualize obstacles to employment, education and integrated living as a civil rights issue, rather than an individual problem of impairments and deficits, made it possible to understand disability that way. Further, an essential prerequisite for the progress of the disability rights movement was the organization of the disability community, a coalition formed by the discovery of each other and the recognition of our common social status. Although medical and educational institutions continue to categorize and divide people by impairment status, the formation and the formulation of the "disability community" has had a major impact in the social/political arena.

For all my early learning, and my ongoing study of disability, it is in reading these histories that I have begun to understand how profound and original the ideas are that drove the early activists. The voices that are heard here demonstrate the purposefulness of the activists and their comprehensive vision of an equitable society. If this research platform were to reveal nothing else, it would be invaluable as a means to contradict the stereotypes of disabled people, and of the disability rights movement as merely riding the coattails and mimicking the agendas of the civil rights and feminist movements.

Yet, not only does this collection of histories serve as an exemplar of social construction and the significance of community, it demonstrates the unique nature of the construction of disability and illustrates the struggle to define and assert rights as a minority group

in the face of powerful efforts to confine disability within the province of medical discourse.

The Value of First-Person Narratives

A second domain that informs this project is the increased attention to the active voice of previously marginalized peoples. First person narratives, long discredited in academic circles, are now accepted by a wide variety of scholars and public historians as not only valid, but necessary research tools. ROHO's intent to bring disabled people's perspective to the forefront is consistent with that approach, and the nuanced and detailed data they obtained demonstrates again the value of the methodology. Disability has traditionally been studied as the effect of war or violence, the failures of medicine, or other causes. In these narratives, we see that what brought disability to the individual becomes much less important than what the presence of disability causes to happen. Significantly, the narrators show the ways that disability sets in motion certain social and institutional responses. As these histories reveal, a disabled person's presence in a school, a restaurant, a job interview, a social gathering, or other venue often caused events to unfold in particular ways.

While scholars outside of disability studies have rarely paid attention to disability narratives, this project provides compelling documentation of the place of disability within the larger social arena, and also demonstrates the ways that disability plays a role in shaping an historic moment. I believe that the rich insights of the narrators and their ability to reveal the complex consequences of disability oppression will engage scholars within disability studies as well as those outside the field. For instance, researchers might want to look at what the histories reveal about the parallels between the place of women in other early civil rights struggles and in the disability rights movement. They may want to examine disabled people's perspective on their exclusion from other social justice platforms or consider the obstacles that the disability community itself may have erected to coalition building with other disenfranchised groups.

Complex Representations of Disability and the Social Milieu

The oral histories provide detailed descriptions of the lives of the narrators and others in their circles. These materials will be useful not only to researchers and activists but to writers and artists interested in portraying the lives of the people interviewed, or developing fictional representations using these figures as stimuli. For instance, writers can turn to these histories for background information for projects that dramatize events of the sixties. The projects might relate specifically to the events or the people described in the oral histories, or the research might be aimed at gaining more accurate information about secondary characters or events. A writer

might want to learn more about what the Cowell Residence really looked like, who lived there, what were the attendants like, some of whom were conscientious objectors doing alternative service during the Vietnam War, or what kinds of wheelchairs and other adaptive equipment were people using then. These histories are about disabled people and the genesis of the disability rights movement, but they are also histories of the period and will be useful in providing more accurate representations of both.

While mainstream cultural products continue to depict disabled people and disabled characters in inaccurate and narrow ways, a growing number of writers, artists, actors, and performance artists who are disabled or are insiders in the disability community are providing more realistic, interesting and complex representations of disability to a wider audience than the arts ever have before. Although the numbers are still small and the venues marginal, I expect that over the next decade, as increasing numbers of disabled people gain access to higher education and training in the arts, their ranks will grow and as they do, this material will continue to grow in value.

A Resource for Disability Studies Scholars

Finally, this project will be an invaluable resource to the growing ranks of disability studies scholars. Disability studies began to take shape as an organized area of inquiry in the early 1980s. Prior to that time, although there were isolated pockets of transformative scholarship in some liberal arts fields, the study of disability was housed almost exclusively in the specialized applied fields (rehabilitation, special education, health, et cetera). Disability studies came along and provided a place to organize and circumscribe a knowledge base that explains the social and political nature of the ascribed category, disability. The field has grown enormously, particularly since the early 1990s, as has the Society for Disability Studies, the organization that supports the work of scholars and activists interested in the development of new approaches that can be used to understand disability as a social, political and cultural phenomenon.

Certain ideas pervade disability studies. For instance, a number of authors have examined such ideas as autonomy and independence. The perspectives employed in a disability studies analysis of such phenomena afford a complex look at these hitherto rarely examined ideas. Scholars interested in the theoretical implications of these ideas will benefit from examining the ROHO histories. They will learn, as I did in a recent reading, how the early activists discovered that the surest route to gaining independence was to have access to attendant care. These young people, many just out of institutions, or living away from home for the first time in their lives, were creating a new type of community, one in which it was clearly understood that support and

services are necessary for individual autonomous functioning. They recognized the irony that what is typically thought of as "total dependence" was instead the ticket to the greatest freedom and autonomy they'd ever known. Rather than wait for the nurse or orderly in their institution to "decide" if it was time to get out of bed, have a shower, eat dinner or watch television, with personal attendants available and under their direction they could make these decisions on their own. Rather than wait at home for their mother or other relative or friend to bring them food or take them somewhere, they could lobby the university for a lift-equipped van that would be at their disposal and provide them with access to the kinds of leisure activities non-disabled students take for granted. They learned by setting up their own wheelchair repair services, and hiring qualified mechanics, they could keep their manual chairs, and the power wheelchairs that they also had lobbied for, in working order.

Through their lived experience they had the occasion to formulate a new way of thinking about such accepted ideas as what constitutes independence; what is freedom, equity, and integration; the ways that physical dependence and psychological independence are two separate and potentially unrelated variables. Disability studies, while dominated by theoretical formulations, social science research methodology, and modes of analysis employed in various areas of the humanities, will benefit enormously from the concrete examples given here of the abstract principles our work depends on.

The value of this project will ultimately be revealed as future research, creative endeavors, and policy initiatives are developed that have utilized this primary source material. Over the decades to come, researchers in all areas of inquiry will find within these documents numerous variables to be tested, relationships among people, events, and trends to be examined, cultural phenomena to be studied and dramatized, and ideas to be woven into theory or literature. The most exciting research opportunity that this work affords is the examination of the beliefs and behaviors of people whose demands for equity and justice upped the ante in the fight for an inclusive society.

The Regional Oral History Office staff are to be commended for their vision. They have brought us a vital piece of history, one that would be lost and forgotten if it were not for them. They have captured in these individual histories, a history. And a legacy.

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New York, New York
April 1999

SERIES HISTORY--The Disability Rights and Independent Living Movement
Oral History Project, by Ann Lage and Susan O'Hara

Historical Framework

The movement by persons with disabilities for legally defined civil rights and control over their own lives took on its present framework in the 1960s and 1970s. Virtually simultaneously in several cities nationwide, small groups of people with significant disabilities joined together to change the rules of living with a disability. No longer content with limited life opportunities, nor willing to be defined solely as medical patients, they shared the willingness to challenge authority, discard received wisdom, and effect societal change that was the hallmark of the era. Not surprisingly, the disability movement paralleled other movements for equity and civil rights by and for racial minorities, women, and gay people. From our vantage at the close of the century, it is apparent that these movements, taken together, have changed the social, cultural, and legal landscape of the nation.

Berkeley, California, was one of the key cities where models for independent living were developed. A small group of young people, all wheelchair users, had one by one enrolled at the University of California in the 1960s. In an era prior to accessible dormitories or private housing, they were given living quarters in the campus's Cowell Hospital. In the midst of the campus maelstrom of free speech, civil rights, and anti-war protests, they experimented with radical changes in their daily lives, articulated a new philosophy of independence, and raised their experience to a political cause on campus and in the community.

By 1972, these students had created new institutions, run by and for people with disabilities, which soon attracted national attention. The first two of these organizations, the Physically Disabled Students' Program on the campus and the Center for Independent Living in the community, drew several hundred people with disabilities to Berkeley from across the United States. This early migration became the nucleus and the strength of the community that, for many, came to symbolize the independent living movement.

Political action kept pace with the developing awareness and institutional growth. In the early seventies, the Berkeley group successfully lobbied the city of Berkeley for curb cuts and the state legislature for attendant care funding. In 1977, scores of persons with disabilities sat in for twenty-six days at the offices of the federal Department of Health, Education, and Welfare in San Francisco, as part of a nationwide protest that eventually forced implementation of Section

504 of the Rehabilitation Act of 1973, often called the Bill of Rights for Americans with Disabilities. Many participants trace their awareness of disability as a civil rights issue and their sense of membership in a disability community to the 1977 sit-in.

By the 1980s, a number of other important organizations had evolved from the Berkeley experience: the Disability Rights Education and Defense Fund (DREDF), the World Institute on Disability (WID), Computer Training Program (later, the Computer Technologies Program [CTP]), the Bay Area Outreach Recreation Program (BORP), and others. All of these organizations shared the original philosophy of the Berkeley movement. Their example and their leaders have had national and even international impact on the quality of life and civil rights of persons with disabilities.

Genesis of the Project

The idea for a project to document these historic events germinated for nearly fifteen years before funding was secured to make possible the current effort. In 1982, Susan O'Hara, then director of the Disabled Students' Residence Program at the University of California, Berkeley, contacted Willa Baum, director of the Regional Oral History Office (ROHO) of The Bancroft Library, suggesting that the genesis of the Berkeley movement be recorded in oral histories with participants in the campus's Cowell Hospital Residence Program. Mrs. Baum and Ms. O'Hara began planning, enlarged the project scope, gathered faculty support, and initiated the search for funding. Their efforts produced three grant applications, the final one in cooperation with Professor Raymond Lifchez of the UC College of Environmental Design, to the National Endowment for the Humanities, none successful.

ROHO then secured funding from the Prytanean Society, a Berkeley campus women's service group, to produce oral histories with Arleigh Williams and Betty Neely, both campus administrators who oversaw the establishment of the early disabled students' programs. Herb Wiseman, a former staff member of the disabled students' program, conducted these two interviews in 1984-1985. Later, the California State Archives State Government Oral History Project funded an oral history with Edward Roberts, the first student in the Cowell program and later the director of the California State Department of Rehabilitation. This initial support proved essential; all three individuals were to die before the current project was funded.

By 1995, as the historical importance of the events in Berkeley and beyond grew increasingly evident, the fragility of the historical record became ever more apparent. The archival records of key institutions that grew out of the movement and shaped nationwide events were not collected and preserved in a publicly accessible library. The

personal papers of key leaders of the movement were scattered in basements and attics. Moreover, the urgency of preserving the memories of participants through oral history interviews was underscored by the death of five pioneer disabled activists in the previous several years.

When Susan O'Hara and Mary Lou Breslin outlined the scope of the problem to The Bancroft Library, the then-curator of Bancroft Collections, Bonnie Hardwick, joined Willa Baum in support of the idea of developing a comprehensive disability collection at Bancroft. Baum, Hardwick, and Ann Lage, associate director of ROHO, worked with leaders of the disability community to design a plan for an archival collection at The Bancroft Library, to include both in-depth oral history interviews and written and photographic records of major organizations and activists. The Disabled Persons' Independence Movement collection was envisioned as "a primary historical resource of national significance, a research platform for future scholars, for persons with disabilities, and for public education." The National Institute on Disability and Rehabilitation Research generously funded the three-year project in 1996.

Project Staff and Advisors

The collaborative nature of the project--among the disability community, academic advisors, oral historians, and archivists--has strengthened it in every respect. The advisory board included three Berkeley professors: Frederick Collignon of the Department of City and Regional Planning, who has worked on disability issues since 1970; Raymond Lifchez, Department of Architecture, who has conducted research on environmental design for independent living since 1972; and William K. Muir, Department of Political Science, who has chaired campus committees on disability issues, and is a scholar of U.S. and state government and public policy. Paul Longmore, professor of history from San Francisco State University and a specialist in disability history, was crucial in defining themes and topics to explore in oral history interviews. Mary Lou Breslin, president and co-founder of the Disability Rights Education and Defense Fund, represented the perspective of the organizations to be documented as well as her personal experiences as an activist for disability rights.

Knowing that oral history is most often successfully carried out by persons who combine a compelling personal interest in the project with an ability to bring a historical perspective to their task, the Regional Oral History Office turned to the Bay Area disability community itself to staff the project's team of interviewers. Susan O'Hara became the historical consultant for the project and conducted a number of interviews as well as informing all of the project activities. All of the project interviewers had personal experience with disability. A majority had significant disabilities, several had participated in or

observed the historical events to be documented and knew many of the key players and organizations. Interviewers included Sharon Bonney, former director of the Disabled Students' Program at UC Berkeley and former assistant director of the World Institute on Disability; Mary Lou Breslin, who crossed over from the advisory board; Kathy Cowan, librarian for a public-interest nonprofit organization; Denise Sherer Jacobson, a writer and educator on disability issues; David Landes, a college instructor of economics and coordinator of student affairs for the Computer Technologies Program.

Joining the team to interview narrators in Washington, D.C, was Jonathan Young, a Ph.D. candidate in American history at the University of North Carolina who had conducted oral histories on the history of the Americans with Disabilities Act. When Mr. Young resigned to accept a White House appointment, Susan Brown, long familiar with disability issues and other civil rights/social movements, became the project's Washington connection. Ann Lage coordinated the interviewing team for the Regional Oral History Office, and the office's regular staff, coordinated by production manager Shannon Page, provided transcription and other clerical support.

Bancroft Library project personnel included Bonnie Hardwick, curator; Lauren Lassleben, supervising archivist; and Jane Bassett, the project archivist whose job it was to contact the disability organizations, project interviewees, and other activists and survey their records to identify historical material. Once records and personal papers were donated to the Library--more than 300 linear feet before the project's conclusion--it was Jane and her student assistant, Amber Smock, who preserved, organized, and made the papers accessible to scholars with detailed finding aids. The archival and oral history projects, though separately administered, were in close cooperation, with the interviewing team providing contacts with the disability community and leads on papers to collect and the archivists assisting interviewers in their research in the growing collection of written records.

Interviewees and Themes

An overarching question for the project was to explore and document how this social movement developed in time, place, and context: how the movement in Berkeley was built, how it became effective, how individual life experiences contributed to and were changed by the movement. Lines of inquiry included identity issues and personal life experiences; social/economic/political backgrounds of individual activists; the roles of women and minorities in the movement; development of leadership; institution building and management; development of a disability community group identity; media, mythology, public image and the political process; impact of technology; the range

of efforts to influence disability law and policy and to embed disability rights into the canon of civil rights.

Interviewees (narrators) were selected for one of several reasons: the individual was a founder or recognized leader of one of the key institutions, made a unique contribution to the movement, was a particularly keen observer and articulate reporter, or was a sustainer of the movement who provided a unique perspective. We attempted to choose narrators who had a range of disabilities and to interview nondisabled persons who contributed significantly to events or institutions.

Interviewees fell primarily into two categories: either they were involved in the residence program of Cowell Hospital on the Berkeley campus in the sixties or they participated in the building of early organizations in the 1970s.

Group One--UC Berkeley's Cowell Hospital Residence Program

A wing on the third floor of Cowell Hospital was the site of the first housing for students with significant disabilities on the Berkeley campus. This cluster became a breeding ground for the Berkeley phase of the independent living movement. About a dozen students--mostly men, mostly white, mainly in their twenties, with more and more autonomy within their grasp--spent several years in this benign but nonetheless isolated hospital residence, in the middle of a campus exploding with student protest movements. Six of these students were interviewed, including Ed Roberts, who narrated several hours of 1960s memories before he died with the oral history still in process. The former students all refer to their sense of community, intense camaraderie, the thrill of independence, an atmosphere of an-idea-a-minute, and the politics of their involvement.

Also included in this first group were certain early university and State Department of Rehabilitation officials--the hospital director, the nurse/coordinator, counselors--who might be called traditional gatekeepers but nonetheless allowed the unorthodox residence program to happen and in some cases encouraged it.

The majority of the narrators in the first group stayed involved in disability-related activities for many more years. Their recorded histories include these later activities, overlapping with the events documented in the second group of narrators.

Group Two--Builders of the Movement

The second group of interviewees are primarily founders and leaders who participated in the expansive phase which began in 1970 with the start of the Physically Disabled Students' Program (PDSP) at the university, followed by the founding of the Center for Independent Living (CIL) in 1972. These interviews reveal the grassroots politics, high energy, occasional chaos, unstinting belief in "the cause", seat-of-the-pants management, funding sources and crises, successes and failures of individuals and organizations. In the next few years a whole constellation of organizations evolved to sustain the independent living movement, including DREDF, CTP, KIDS, BORP, WID, Center for Accessible Technology (CAT), and Through the Looking Glass. This group of interviewees provide insight into the politics, leadership, and organization-building of both their own organizations and CIL.

Many key interviewees in this group are still in leadership positions and have had national and international impact on disability policy development. Also included in this second group are persons who were not in the top ranks of leadership but who were keen observers of the scene, could augment the basic history, and offer further points of view.

Oral History Process

All of the project interviewers received formal and informal training in archival oral history procedures and met monthly as a group to plan and evaluate interviews and review progress. Interviewers prepared a preliminary outline before each interview session, based on background research in relevant papers, consultation with the interviewee's colleagues, and mutual planning with the interviewee. In-depth tape-recorded interview sessions were from one to two hours in length; interviewees required from one to fifteen sessions to complete their oral histories, depending on the length and complexity of their involvement in the movement.

Tapes were transcribed verbatim and lightly edited for accuracy of transcription and clarity. During their review of the transcripts, interviewees were asked to clarify unclear passages and give additional information when needed. The final stage added subject headings, a table of contents, and an index. Shorter transcripts were bound with related interviews into volumes; longer transcripts constitute individual memoirs.

More than forty oral histories are included in this first phase of the Disabled Persons' Independent Movement project. Volumes can be read in the Bancroft Library and at the University of California, Los Angeles, Department of Special Collections. They are made available to

other libraries and to individuals for cost of printing and binding. Many of the oral histories are accompanied by a videotaped interview session to document visual elements of the interview and the setting in which the interviewee lives or works. Video and audiotapes are available at The Bancroft Library. If funding for a second phase of the project is secured, many of the oral history transcripts as well as a representative collection of documents and photographs will be available on the Internet as part of the Online Archive of California.

The Regional Oral History Office was established in 1954 to augment through tape-recorded memoirs the Library's materials on the history of California and the West. The office is under the direction of Willa K. Baum, Division Head, and the administrative direction of Charles B. Faulhaber, James D. Hart Director of The Bancroft Library, University of California, Berkeley. The catalogues of the Regional Oral History Office and many oral histories on line can be accessed at <http://library.berkeley.edu/BANC/ROHO/>.

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Ann Lage, Project Coordinator
Susan O'Hara, Historical Consultant

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The Formative Years in Berkeley, California

Single-interview volumes

Mary Lou Breslin, *Cofounder and Director of the Disability Rights Education and Defense Fund, Movement Strategist, 2000.*

Joel Bryan, *Founder and Director of Disabled Students' Services, UC Riverside and UC Davis, 2000.*

Kitty Cone, *Political Organizer for Disability Rights, 1970s-1990s, and Strategist for Section 504 Demonstrations, 1977, 2000.*

Charles Grimes, *Attendant in the Cowell Residence Program, Wheelchair Technologist, and Participant/Observer of Berkeley's Disability Community, 1967-1990s, 2000.*

Deborah Kaplan, *National Policy Advocate and Leader of Disability Rights Organizations, 1976-1990s, 2000.*

Johnnie Lacy, *Director, Community Resources for Independent Living: An African-American Woman's Perspective on the Independent Living Movement in the Bay Area, 1960s-1980s, 2000.*

Joan Leon, *Administrator at Berkeley's Center for Independent Living and the California Department of Rehabilitation, Cofounder of the World Institute on Disability, 2000.*

Susan O'Hara, *Director of the UC Berkeley Disabled Students' Program, 1988-1992, Coordinator of the Residence Program, 1975-1988, and Community Historian, 2000.*

Corbett O'Toole, *Advocate for Disabled Women's Rights and Health Issues, Founder of Disabled Women's Alliance, 2000.*

Zona Roberts, *Counselor for UC Berkeley's Physically Disabled Students' Program and the Center for Independent Living, Mother of Ed Roberts. Appended: Jean Wirth, Counselor at the College of San Mateo and Early Mentor to Ed Roberts, 2000.*

Susan Sygall, *Cofounder and Director of Berkeley Outreach Recreation Program and Mobility International USA, Advocate for Women's Issues, 2000.*

In Process, single-interview volumes:

Judy Heumann, Deputy director of the Center for Independent Living, cofounder of the World Institute on Disability, assistant secretary of the U.S. Department of Education. (in process)

Arlene Mayerson, Directing attorney, Disability Rights Education and Defense Fund. (in process)

Pat Wright, Director, Governmental Affairs Office of the Disability Rights Education and Defense Fund, strategist for the Americans with Disabilities Act. (in process)

Multi-interview volumes:

UNIVERSITY OF CALIFORNIA'S COWELL HOSPITAL RESIDENCE PROGRAM FOR PHYSICALLY DISABLED STUDENTS, 1962-1975: CATALYST FOR BERKELEY'S INDEPENDENT LIVING MOVEMENT, 2000.

Edward V. Roberts, *The UC Berkeley Years: First Student Resident at Cowell Hospital, 1962.*

James Donald, *Student Resident at Cowell, 1967-1968, Attorney and Deputy Director of the California Department of Rehabilitation, 1975-1982.*

Cathrine Caulfield, *First Woman Student in the Cowell Program, 1968.*

Herbert R. Willsmore, *Student Resident at Cowell, 1969-1970, Business Enterprises Manager at the Center For Independent Living, 1975-1977.*

Billy Charles Barner, *First African American Student in the Cowell Program, 1969-1973, Administrator in Disability Programs in Los Angeles.*

John "Jack" Rowan, *Student Resident at Cowell, 1971-1973, and Chair of CIL's Board of Directors, 1976-1982.*

Peter Trier, *Student at Berkeley: Transition from the Cowell Hospital Program to the Residence Halls, 1975.*

UC BERKELEY'S COWELL HOSPITAL RESIDENCE PROGRAM: KEY ADMINISTRATORS AND CALIFORNIA DEPARTMENT OF REHABILITATION COUNSELORS, 2000.

Henry Bruyn, *Director, Student Health Services, 1959-1972.*

Edna Brean, *Nurse Coordinator, Cowell Residence Program, 1969-1975.*

Lucile Withington, *Department of Rehabilitation Counselor, Cowell Residence Program, 1969-1971.*

Karen Topp Goodwyn, *Department of Rehabilitation Counselor in Berkeley, 1972-1983.*

Gerald Belchick, *Department of Rehabilitation Counselor, Liaison to the Cowell Program, 1970s.*

John Velton, *Department of Rehabilitation Administrator: Providing Oversight for the Residence Program, Fostering Career Placement and Computer Training, 1970s-1980s.*

BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY VOLUME I, 2000.

Herbert Leibowitz, *Research and Training Specialist for the Rehabilitation Services Administration, 1971-1990.*

Mary Lester, *Grant Writer for the Early Center for Independent Living in Berkeley, 1974-1981.*

Bette McMuldren, *Assistant to Judy Heumann and Grant Writer at the Center for Independent Living, 1975-1980.*

Kenneth Stein, *Public Information Coordinator for the Center for Independent Living and Participant/Observer of the Disability Movement.*

BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY
VOLUME II, 2000.

Carol Fewell Billings, Attendant and Observer in the Early Days of the Physically Disabled Students' Program and the Center for Independent Living, 1969-1977.

Michael Fuss, Attendant for Cowell Residents, Assistant Director of the Physically Disabled Students' Program, 1966-1972.

Linda Perotti, An Employee Perspective on the Early Days of the Cowell Residence Program, Physically Disabled Students' Program, and the Center for Independent Living.

BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY
VOLUME III, 2000.

Eric Dibner, Advocate and Specialist in Architectural Accessibility.

Hale Zukas, National Disability Activist: Architectural and Transit Accessibility, Personal Assistance Services.

BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY
VOLUME IV, 2000.

Janet Brown, Student Member of the National Federation of the Blind and First Newsletter Editor for the Center for Independent Living, 1972-1976.

Phil Chavez, Peer Counselor at the Center for Independent Living, 1970s-1990s.

Frederick C. Collignon, UC Professor of City and Regional Planning: Policy Research and Funding Advocacy.

Hal Kirshbaum, Director of Peer Counseling at the Center for Independent Living.

Michael Pachovas, Berkeley Political Activist, Founder of the Disabled Prisoners' Program.

Raymond "Ray" Uzeta, Independent Living Centers in Berkeley, San Francisco, and San Diego: Perspective on Disability in Minority Communities.

BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY
VOLUME V, 2000.

Jacquelyn Brand, *Parent Advocate for Independent Living, Founder of the Disabled Children's Computer Group and the Alliance for Technology Access.*

Doreen Pam Steneberg, *Parent Advocate for Educational Rights for Children with Disabilities.*

MAINSTREAM MAGAZINE: CHRONICLING NATIONAL DISABILITY POLITICS, 2000.

Cynthia Jones, *Mainstream Magazine Editor and Publisher.*

William Stothers, *Journalist and Managing Editor of Mainstream Magazine.*

UNIVERSITY ADMINISTRATORS RECALL ORIGIN OF THE PHYSICALLY DISABLED
STUDENTS' RESIDENCE PROGRAM, 1987.

Arleigh Williams, *Recollections of the Dean of Students.*

Betty H. Neely, *Recollections of the Director of Student Activities and Programs.*

In Process, multi-interview volumes:

Neil Jacobson, *Cofounder of the Computer Training Project and Cochair of the President's Committee on Employment of People with Disabilities.*

Scott Luecking, *Cofounder of the Computer Training Project, Specialist in Accessible Technology. (in process)*

Maureen Fitzgerald, *Early Deaf Services Programs at the Center for Independent Living. (in process)*

Anita Baldwin, *Deputy Director of the Center for Independent Living, Early 1980s: Observations of Blind Services and Staff Strike. (in process)*

Joanne Jauregui, *Activist in the Deaf Community: Deaf Services at Center for Independent Living. (in process)*

VIDEOTAPED INTERVIEWS:

Mary Lou Breslin, Kitty Cone, Neil Jacobson, Joanne Jauregui, Deborah Kaplan, Johnnie Lacy, Joan Leon, Susan O'Hara, Zona Roberts, Ken Stein, Herb Willsmore, Hale Zukas.

Regional Oral History Office
The Bancroft Library

University of California
Berkeley, California

Disability Rights and Independent Living Movement Oral History Series

BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY
VOLUME V

Jacquelyn Brand

PARENT ADVOCATE FOR INDEPENDENT LIVING, FOUNDER OF THE DISABLED CHILDREN'S
COMPUTER GROUP AND THE ALLIANCE FOR TECHNOLOGY ACCESS

An Interview Conducted by
Denise Sherer Jacobson
in 1998 and 1999



Steve, Jackie (Betts laureate of 1992), Judith, and Michelle Brand at the Betts Award Ceremony at the Library of Congress, November 1992.

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INTERVIEW HISTORY--Jacquelyn Brand

Jacquelyn Brand was invited to participate in the Disability Rights and Independent Living Movement Oral History Series because of her leadership in promoting the development of assistive technology for people with disabilities. As a former teacher of disadvantaged youth, her approach had always been to find creative solutions to facilitate her students' education. Consequently, she applied the same approach when challenged by the issues of raising her significantly disabled daughter, Judith, with the goal of helping her move toward independent living through the use of assistive technology.

Ms. Brand's six interview sessions from August, 1998 to March, 1999 alternately took place in her San Rafael home and the interviewer's Oakland home office. Jackie and husband Steve live in a spacious and comfortable, wheelchair accessible house, complete with baby grand piano--Jackie once dreamed of being a concert pianist--in a quiet, upscale, residential neighborhood. The interviews at the Brands' took place on weekends in the kitchen/dining area overlooking their backyard pool. There were periodically brief interruptions--phone rings, noisy pool maintenance, the sight of a deer grazing along the forest-like backyard hillside, and a parting goodbye from their youngest daughter, Judith, who was on her way home after a swim in her parents' pool. Both interviewer and interviewee have known each other socially for more than fifteen years. It was interesting to witness the ease and respect between Jackie and Judith that has developed over the years.

The highlights of the interview include Jackie's recount of networking with parents, professionals and the business community to create such locally and nationally successful organizations as the Center for Accessible Technology (formerly Disabled Children's Computer Group) and the Alliance for Technology Access. Jackie's earlier work included curriculum design and development for the KIDS Project at Berkeley's Center for Independent Living, where she formed long-lasting friendships with people with disabilities. She has valued these relationships for the wealth of knowledge and experience she gained that has enhanced her skills in parenting a child with a disability. She also recalls CIL's general reluctance to welcome parents and her own struggle to enlist parent involvement in support of the 504 demonstration of 1977. The interview additionally explores the Brands' efforts to offer Judith the full range of life experiences in each step of her development.

Particularly poignant are Jackie's observations of her two daughters as they were growing up--the older one, Michelle, not disabled, and Judith, who has a disability caused by surgical complications during infancy. Jackie gives unique and valuable perspective as a parent involved in the

movement to help her daughter achieve maximum independence by constantly confronting the confines of society and existing bureaucratic systems.

The transcript was lightly edited by the interviewer and reviewed by Jackie, who added further comments to clarify portions of the interview. She also informed us that after the oral history was completed, Judith returned to the use of her birth name, Shoshana.

The interview tapes are available for listening in the Bancroft Library. Jackie Brand also donated to the library an eleven-minute video, *QUALITY OF LIFE: ALLIANCE FOR TECHNOLOGY ACCESS* which features segments of the interviewee's discussion on the applications of assistive technology for people with disabilities.

The Regional Oral History Office was established in 1954 to augment through tape-recorded memoirs the Library's materials on the history of California and the West. Copies of all interviews are available for research use in The Bancroft Library and in the UCLA Department of Special Collections. The office is under the direction of Willa K. Baum, Division Head, and the administrative direction of Charles B. Faulhaber, James D. Hart Director of The Bancroft Library, University of California, Berkeley.

Denise Jacobson
Interviewer-Editor

June 15, 2000
Regional Oral History Office
The Bancroft Library
University of California, Berkeley

Regional Oral History Office
Room 486 The Bancroft Library

University of California
Berkeley, California 94720

BIOGRAPHICAL INFORMATION

(Please write clearly. Use black ink.)

Your full name Jacquelyn Palmer Brand

Date of birth 9/16/43 Birthplace Los Angeles, CA

Father's full name Morris Palmer

Occupation retired Birthplace Mexico City, Mexico

Mother's full name Thelma Caryl Palmer

Occupation unemployed Birthplace Brooklyn, NY

Your spouse Stephen Hancock Brand

Occupation Chemistry teacher Birthplace Altadena, CA

Your children Michelle, 27

Judith (aka Shoshona), 23

Where did you grow up? Los Angeles, CA

Present community San Rafael, CA

Education A.B., UC Berkeley

Teaching Credential, UC Berkeley

Occupation(s) ^{school} teacher, community organizer, music

teacher, nonprofit management, consulting

Areas of expertise education, assistive technology,

organizational development

Other interests or activities music, reading, travel

Organizations in which you are active Alliance for Technology Access,

California Community Technology Foundation Center

for Accessible Technology, Wheelwind Wheelchairs

International Through the Linking Glass

VITA

Jacquelyn Brand

312 Riviera Drive

San Rafael, CA 94901

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(fax) 415-457-1432

e-mail: jackieb@pacbell.net

EDUCATION

B.A., University of California, Berkeley, 1965.

Lifetime Teaching Credential, California, 1966

*PROFESSIONAL EXPERIENCE***President, Independent Living Network, San Rafael, CA**

Founder and director of program to support community based independent living services for adults with disabilities. 1997 - present,

Coordinator, Universal Service Alliance, San Rafael, CA

Founder and coordinator of alliance of community groups promoting universal access by underserved communities to advanced telecommunications technologies and services. 1995 - present.

Executive Director, Alliance for Technology Access, San Rafael, CA.

Founder and director of a national network of community-based resources centers providing access to technology for children and adults with disabilities. 1987 - 1996

Consultant, Apple Computer, Inc., Cupertino, CA.

Consulted with the Office of Special Education and Rehabilitation at Apple to develop a coalition of nonprofit organizations and technology vendors. 1986 - 1989

Executive Director, Disabled Children's Computer Group, Berkeley, CA.

Founder and director of a community-based technology resource center for individuals with disabilities, family members and educators. 1983 - 1988

Resource and Technology Coordinator, PLAE, Inc., Berkeley, CA.

Coordinator of programs and environments which integrate disabled and non-disabled children in learning and recreation programs. 1983 - 1985

Curriculum and Resource Developer, KIDS PROJECT, Center for Independent Living, Berkeley, CA. Curriculum developer and trainer for model training program for parents, students, and teachers to facilitate mainstreaming of children with disabilities into public school programs. 1980-1983

Teacher, San Francisco Public Schools, S.F., CA.

Teacher of Reading, English, English as a Second Language, and Social Studies. Counselor for low achieving students. Developer of original proposal for new school for truant and low achieving high school students. 1966 - 1981

BOARDS, PANELS AND TASK FORCES

- Access by Design - Member - 1996 - present
- Computers in Our Future, Member, 1996 - present
- Governor's Council on Information Technology - Member - 1994 - present
- Apple Computer Home Learning Advisory Council - Member - 1994 - present
- Consortium for AT Leadership and Systems Change - Member - 1994 - present
- New Mexico Technology Deployment Project - Advisory Board - 1994 - present
- Public Interest Center on Long Term Care - Board Member - 1994 - 1997
- American Assoc. for the Advancement of Science Nat'l Planning Council - Member - 1993 - present
- Telecommunications Consumer Advisory Panel for Pacific Bell - Member - 1993 - 1996
- Archimedes Project, Stanford University, Palo Alto, CA - Advisory Board Member - 1993 - present

- Rehab Engineering Tech Training Program, CSU, SF, CA - Advisory Board Member - 1987, 1993
 - Director's Task Force on Assistive Technology, CA Dept. of Rehab - Member - 1991-present
 - U.S. Delegation to Prague with National Council on Disability - Member - 1992
 - World Institute on Disability Blue Ribbon Comm. on Telecommunications Policy - Member - 1991
 - Feasibility Study on Nat'l Assistive Technology I & R Network, Columbia, S.C. 1990
 - Bridge School, Hillsborough, CA - Advisory Board Member - 1989 - present
 - California Consortium on Technology - Executive Committee Member - 1988 - 1990
 - Center for Special Education Technology, Reston, VA - Advisory Board Member - 1988
-

SELECTED PRESENTATIONS

Keynote Addresses on Technology and Disability

- IBM Education Forum, Las Vegas, NV 1996
- National Science Found. AAAS Invitational Conference on Learning Disabilities, Washington DC, 1995
- Tech 2000: Emerging Trends in Assistive Technology, St. Paul, MN, 1994
- Conference on Advocating for Assistive Technology, Erlanger, KY, 1994
- Hawaii Assistive Technology Conference, Honolulu, HI, 1993
- Pacific Northwest Conference on Technology, Seattle, WA 1993
- Occupational Center of Central Kansas, Salina, KS 1993
- Henry B. Betts Award Luncheon, Library of Congress, Washington, DC 1992
- Conference on Assistive Technology, Stockton, CA 1991
- UCPA, Assistive Technology Conference, Denver, CO 1990
- Resource Center for Independent Living Annual Conference, Utica, NY 1990
- ConnSENSE, University of Connecticut, Storrs, CT 1989
- Detroit Institute for Children, Detroit, MI 1989
- Clark County Schools Conference on Special Education and Technology, Las Vegas, NV 1987

Other Significant Presentations

- Convener, Consumer Summit on Telecommunications, Alexandria, VA, 1996
- Software Publisher's Association National Meetings, San Francisco, CA, 1994 & 1996
- Goals 2000 Satellite Meeting with Secretary of Education Riley, Washington, DC, 1993
- Assistive Technology Exhibit, Intel Corp., Mt. View, CA 1993
- Coup de Tech International Conference on Technology, Apple Computer, Cupertino, CA 1993
- Eastern European Conference on Disabilities, member of American delegation, Prague, CZ. 1992
- American Association of Occupational Therapists, Cincinnati, OH 1992
- Public Forum of the National Council on Disability, Financing Assistive Technology 1991
- Video Teleconference on Communication Aids & Devices, U.S. Dept. of Ed., Norfolk, VA 1989
- Council for Exceptional Children Annual Convention, 1989
- International Conference on Special Education, Beijing, China 1988
- American Association for the Advancement of Science, Kansas City, MO 1988
- Technology for People with Disabilities Conference, CSU, Northridge, CA, 1988 - present
- Closing the Gap Annual Technology Conference, Minneapolis, MN, 1987 - present
- Co-Host, Teleconference for WHRO TV, Norfolk, VA 1987
- Applefest Conference, San Francisco, CA 1987

AWARDS

- Martin Luther King Community Service Award, Marin County, CA 1997
- Strache Leadership Award, Los Angeles, CA 1993
- Henry B. Betts Laureate, Library of Congress, Washington, DC 1992
- Family Hall of Fame Inductee, Exceptional Parent Magazine, Boston, MA 1992

PERSONAL

Parent of 2 children including an adult daughter with disabilities.

Biographical Information on Jacquelyn Brand

As the founder and original executive director of the Alliance for Technology Access, Ms. Brand used her extensive skills and existing network of contacts to develop an organization that is a vast network of linked resources focused on providing access to technology for people with disabilities. The Alliance, now a nationally recognized leader in the field, consists of 42 consumer-directed technology Resource Centers and 70 technology vendors and developers.

Ms. Brand is an educator and a community leader. After graduating from the University of California, she worked on a project training high school students to tutor low achieving elementary school students in the ghettos of Richmond, CA. She then taught at-risk high school students in the San Francisco Public Schools for over ten years and helped develop a new high school for truant and low-achieving students.

In 1981, Ms. Brand joined with the Center for Independent Living and turned her energies toward the development of a model training program for parents, students and teachers to use in facilitating the mainstreaming of children with disabilities into public school programs.

Motivated by the needs of their daughter Judith, in 1983 Ms. Brand and her husband Steve began to search for ways in which technology could be harnessed to provide Judith with access to her world. It was this search that started the Disabled Children's Computer Group (now called the Center for Accessible Technology) in Berkeley, a community-based technology resource center focused on the needs of people with disabilities. DCCG soon attracted the attention of Apple Computer's Worldwide Disability Solutions Group which hired Ms. Brand as a consultant to help them replicate the DCCG model nationally and form the Alliance for Technology Access.

Ms. Brand was the Executive Director of the Alliance for Technology Access from 1987 to 1996. As a spokesperson for the Alliance and a strong advocate for the rights of individuals with disabilities to access conventional, assistive and information technologies, Ms. Brand has testified in front of congressional hearings, has joined the National Council on Disabilities envoy to Prague, keynoted many major conferences and been awarded the 1992 Henry B. Betts Award for her efforts toward enhancing the lives of individuals with disabilities.

In 1995, Ms. Brand became a leading proponent of access to emerging telecommunications technologies by all people and is coordinator of the Universal Service Alliance (USA). USA is a coalition of community leaders and organizations concerned with access for communities at greatest risk of being excluded from the nation's information infrastructure as it develops and becomes the key to future employment and education.

Currently, Ms. Brand is developing a model of coordinated service delivery for students transitioning from the public schools into the next phase of life. Through the Independent Living Network Ms. Brand is using her skills at locating, coordinating and maximizing the use of community resources to support the goals of individuals with disabilities.

INTERVIEW WITH JACQUELYN BRAND

I EARLY YEARS THROUGH COLLEGE, MARRIAGE, TEACHING CAREER,
STARTING FAMILY, 1943-1974

[Interview 1: August 10, 1998] ##¹

Childhood--A Mixture of Politics and Pragmatism

Jacobson: Jackie, let's start off with you telling me when and where you were born and tell me about your family.

Brand: All right. I was born September 16, 1943 in Los Angeles. I come from the east part of L.A., a very poor neighborhood, actually, of mostly Mexican Americans and some older Jewish people--it's called Boyle Heights--and lived there for the first number of years of life in very, very tiny little apartments and in one case a reconverted garage, actually.

My dad had come not very long before from Mexico where he was born and grew up. He came with his parents and so my grandparents lived there.

My mom was from New York and was basically raised by her grandmother and her grandmother's dozen or so kids and had lived in a very poor section of Brooklyn.

I spent the first number of years in L.A. with my parents--my parents were very young. My mom was fifteen, my dad was sixteen when they got married. When I came along they were sixteen and seventeen years old, so they were still babies themselves. I have one sister, who's three and a half years younger than me. I was the first born.

¹## This symbol indicates that a tape or tape segment has begun or ended. A guide to the tapes follows the transcript.

Over the years my dad was the main bread-winner. My mom was at home with us. And my dad did a lot of different things. He didn't speak good English for a long time, so he struggled getting jobs. He worked here and there and everywhere and he always worked at least one job and often more than one and basically kind of pulled us all up by his bootstraps. As he began to make a little bit of money, we moved a little west into the better sections of L.A., with his motivation being to get us into decent schools.

I remember going to his high school graduation. He graduated at night when we were--gosh, I don't know how old we were, but I remember it. It was a big deal in our family to have him graduate high school. I don't think my mother ever did. And I became one of the early ones to go to college, actually. That was a very big deal in our family.

We're a very close-knit family and we were always expected to be good achievers. We moved a lot. I went to six elementary schools and so we had a fairly rough, but not--to me as a kid, it seemed like a good childhood.

I had to be a grown-up to realize the fact that--I never had store-bought clothes, but clothes that my grandmother made --I wore wonderful clothing, but to me, I always felt badly that we never had store-bought clothing until we were quite a bit older.

As I grew up--when I graduated high school, I went to college at UC Berkeley. It was a very big deal. I went away to school. And it was not easy to do, but the UC system was relatively inexpensive and so that was really the only chance that I could go away to school, was to be in the UC system.

Jacobson: How did your mother get from Brooklyn--

Brand: --to California? One of my mom's aunts was asthmatic and they went to Phoenix, Arizona, for the climate. They didn't like it so they continued west to Los Angeles. My mom was eight years old at the time. It's funny, we were just in New York, as you know, for Michelle's graduation, and we did a little "Roots" trip with my mom. We went into Brooklyn and tried to find some of the places where she had lived and we found the streets and she remembered an amazing amount, but none of the places were there; they had all been ripped down. I know that she had desperately wanted to get out of New York. In fact, when we first talked about this trip to New York and talked about going to Brooklyn she didn't want anything to do with it because she had such negative memories of tremendous poverty--twelve in a

room, or six in a bed, or whatever it was. I know that she would have grabbed any opportunity to leave New York and I think she grabbed the first--an early opportunity to get married as a way to escape parts of her life that were really, really tough, and to look for a way to begin build a new life with my dad. It's kind of amazing, they've been married over fifty years now and that's kind of extraordinary given the way that they started.

Jacobson: You said that she was raised by her grandparents?

Brand: Her grandmother, actually.

Jacobson: Her grandmother. How did that happen?

Brand: I think it was a function of the fact that her own mother was off doing different things and didn't have the stability or maybe the commitment to raising my mom. There are a lot of feelings about that actually. Although my mother was an only child, she felt a lot like she had a lot of siblings because she was raised in a house with so many aunts and uncles who were more her age than not. My grandmother raised all these kids alone. The story about her husband was that he came around about once a year just long enough to produce another child, [wry laughter] and took off and left my grandmother to take care of things.

My grandmother was a very devoutly religious orthodox Jewish woman and somehow, I don't know, there was a--I was going to say a simplicity of faith that allowed her to kind of put one foot in front of her day-by-day and manage somehow to feed all those mouths. I don't know how she did it. But eventually they all found their way to Los Angeles.

On my dad's side, at the age of about fourteen or fifteen, he drove his parents from Mexico to Los Angeles to settle in the United States, looking for new opportunities.

Now they had managed to come to Mexico from eastern Europe; they were Jews, also, and came to Mexico, I guess, because the opportunity was there, instead of settling in the United States. And to this day I have a huge family in Mexico which is now a much more assimilated family, so though it had a Jewish beginning, my family now is a combination of Jews and non-Jews. There are family reunions periodically there and so that most of the family did not follow my grandparents to Los Angeles.

His parents were very politically active--they were anarchists. I grew up spending weekends with them and going to all of their workers meetings and picnics and fundraisers and so I grew up with a strong activist political sense. And also I think what I got from them is some feeling that whatever the reality of the day was didn't have to be. You could always have a vision of a future that you could work to create that was different from the present.

Jacobson: So it sounds like they had a lot of influence on your way of thinking?

Brand: Yes, they did. I think they did--that grandparents can have an influence on grandchildren that sometimes parents can't have on children. That separation of generations, I think, allowed for me to really benefit a lot. I spent a lot of time with them as a child growing up, partly because my parents were children trying to deal with parenting and life and making a living. And my grandparents' lives were really made meaningful by the political work that they were involved in. I grew up with the stories about my grandparents knowing Lenin and Krupskaya. I read my grandmother's account of the hunger strike she led in a Siberian prison where she was imprisoned for her political beliefs in Russia, and I heard stories of my grandfather breaking into a prison somewhere and springing--liberating my grandmother. There was magic for me in a lot of those stories.

My grandfather spoke and wrote in at least eight languages. He began the first newspaper in Mexico devoted to birth control in a poor Catholic country. So they weren't much defined by their--they weren't limited by their times. I think that's one of the things I learned from them. I admired them.

My father is interesting. Though I think he was very influenced by them, he also had to deal with the flip side of when you're always in political meetings, which is you're not home for your kids and so he had a lot of the negative results of some of those things. And there were some very negative things. He grew up more of a pragmatist and I was very influenced by that, too, actually.

My grandparents had this little old shmatteh store--a little general store in east L.A. in Boyle Heights--where they sold a little of this and a little of that to make a living. My grandfather would sit in the store dreaming about the revolution, while people would be helping themselves to anything they wanted in the store. [laughs] My grandmother was more the pragmatist of the couple and without her I think they would have gone out of business in a heartbeat.

My father grew up realizing that he had to support them very early on. He worked very hard at a very tender age, didn't have the benefit of a childhood because they had their politics and somebody had to put bread on the table. Very early in his life he became that pragmatic person who said, you know, "What good are your politics, if you can't support yourself and take care of your children?" And so he was in some ways a reaction to them.

And in some ways, I think I'm this match, this mix of wanting to have the dream, but also really being rooted in the reality of, "But this is where we are today and what are you going to do tomorrow?" So I'm kind of a mixture of the two generations, actually. I've never really thought of it in that way, but I think as I reflect on it, that that's the case.

Jacobson: Now did your mother's grandmother come from Europe?

Brand: Yes. She's eastern European, born in Lithuania. My grandfather was from Poland on my father's side. My grandmother on my father's side was from Russia. My grandmother on my mother's side--she was older and didn't ever speak much English. Although everybody always said she had a great sense of humor, I didn't get most of it because it was in Yiddish. I did pick up a certain amount of Yiddish but not enough to get the subtleties of her humor.

Jacobson: Did you say that your father is an only child?

Brand: No, he has a younger sister who is about seven or eight years younger than he is. In fact, that was very significant in his life because not only was he left on his own an awful lot, that meant that he had a lot of responsibility for his sister whose name--my dad's name was Mauricio, or Morris, and his sister's name was Armonia, which is the Spanish word for Harmony. Her birth was a hope to bring more harmony into the relationship of my grandmother and grandfather who had a pretty tough relationship. We call her Armony in English. So Armony was quite a number of years younger and was raised to a large degree by my dad. He was old enough to really watch out for her and dictate a lot to her, and he created plenty of grief for her when she wanted to grow up and date. My father was very conservative and dictatorial where she's concerned.

Actually, my father was so young when he became a father and Armony was enough years younger than he was that she was closer in many ways to me as we grew up. She's right between the two generations and since my father isn't really a full generation older than I am, Armony connected a lot with me. I

remember when I was young she used to say, "I pity you when you get to be dating age. Your father is [laughter] going to never let you go out with anybody. He used to beat up my boyfriends." So he had some of the macho Mexicano in him in his youth and was very worried about and overprotective of Armony. He eased up a little bit when I came along, and then when my sister came along he finally got tolerable about some of these issues. [laughs]

High School Interests, Branching out from Jewish Culture

Jacobson: What were your interests as a child or in high school?

Brand: I always loved music. I've played the piano from a very early age and it was always my hope that I'd grow up and be a concert pianist, actually. That was my early goal in life. I was fairly talented and I practiced and studied very hard. In high school I practiced three hours a day, for example, just to give you an idea of how serious I actually was.

I was also a very hard-working student. I don't think I was the best student by a long shot, but I was a hard-working student. And because I switched schools a lot, I was always trying to build a place for myself in a school. As a result I grew up, I think, extraordinarily concerned about and then skilled in relationships with people because I had to develop that capacity. There were always new people.

And that translated into a lot of involvement in student government when I was in junior high and high school. I was girl's league president. I was an over-achieving first child type and very involved in student government issues--not very savvy; very naive, in fact. When I look back, I can't believe some of the things that I did, [laughs] which I will not share. [laughter] But I was also very oriented toward other people's approval, which is something that I didn't admire in myself very much. I think that I've grown into an adult who has more of an internal idea of what I wanted to do, but I think I still struggle with that a lot. I recall myself as a goody-two-shoes in elementary school and junior high school.

Jacobson: Did you get a lot of support and encouragement from your parents?

Brand: I got a lot of support for being a good student and doing the right thing and being acceptable. When I got into high school

I became a little bit more counterculture in my view of the world--and then leaving to go to UC Berkeley created some alienation from my family. In fact, my parents and I didn't speak for a while. They disapproved of my lifestyle and I felt rejected by them. But in the end family and children in our family are extremely valued and loved, especially young children, and we've remained very close.

As we got older there were tremendous expectations for us to make them proud, which probably every family has to some degree. But they had grown up in such poverty and felt so invalidated--my dad had desires, academic desires he could never fulfill and so he wanted to see us fulfill some of those hopes and dreams he had had for himself. He wanted to be a doctor, but there was no way. He had to go out and earn a living and get a job doing whatever he could find.

Both my parents are very bright. The fact that they don't have formal education is unrelated to their intellectual capacity. And my dad eventually turned that into a tremendous knowledge of business and ability to start businesses and make money that way. They have done incredibly well as a team in working together in a lot of the things that they've done.

But I think the problems came when I began to want to do things that were a little out of the mainstream. That troubled them and they had a lot of difficulty with it.

Jacobson: Well, like what?

Brand: Well, earlier on, one of the typical Jewish things, I think, was the idea of dating somebody who wasn't Jewish--that was horrifying to them. And actually as a result, I don't think I ever dated anybody that was Jewish. [laughter] That was funny. It was things like dressing a certain way and hairstyles and going to events--the mainstream events which I tended not to be too interested in. I was more a loner type. Even though I was very popular and I was an officer and all that stuff, as I grew older, I could see my real inclinations were in a little different areas stylistically, fashion-wise, and then eventually just in my studies and everything I did--and eventually very much in my politics, so we had a lot of distinctions.

Jacobson: Were they very religious Jews?

Brand: No, it was more cultural. In fact, they are both atheists and had a kind of a crisis in their whole religious upbringing at a certain point when I was a young teenager when a thirteen-year-

old cousin died. She died unnecessarily in a terrible tragedy and her parents and her family had been very religious and it led them to just totally reject the religious aspect to the degree that they had bought into it.

But they are strong cultural Jews, and so for example, I went to a little bit of religious school, more because I wanted to--it wasn't their pushing at all. I didn't get a bat mitzvah, or anything like that. They didn't particularly believe in that and so, yes, it was very much more cultural.

And my grandparents on my father's side were total atheists, totally anti-religious as anarchists; my grandmother on my mother's side was an orthodox Jew--extremely religious, so I saw both ends of the spectrum.

University of California, Berkeley, 1961

Jacobson: After high school, what made you decide to go to Berkeley?

Brand: I think at a certain point--it's interesting, at a certain point my parents and I both agreed it would be important for me to see some other part of the world, to get a little separation from the environment I was in and to be on my own, apart from the family. And Berkeley was the obvious place. UC Santa Cruz didn't exist, UC San Diego didn't exist at the time--I don't know how many campuses there actually were, but UC Berkeley sounded like the perfect place to me. [laughter] They were willing, I had good enough grades and it was reasonable, so UC Berkeley was the choice. I knew that the money wasn't there to have any kind of private school education at all, and that I was going to have to work hard to get through a public school. At that point the state colleges and community colleges were not seen as a good option as they are today. They play a different role today than they did at my time when I was going away to college. The only sort of honorable place to be would be a university.

Jacobson: And what year was that?

Brand: I started at UC Berkeley September of 1961, so I graduated from high school June of '61. The other thing that had happened, I just remembered, was this was also the year that my parents moved to Mexico. My dad decided he had a good business opportunity with family members and he moved back. The idea was they wanted me to move to Mexico. In Mexico they were in a

more upper class society. Many of the family members were wealthier. You have a family in Mexico, too, I just remembered.

Jacobson: No, I don't.

Brand: No? I was thinking--okay. It's funny, I wonder why I thought that. Well, anyway, the last thing I wanted to do was live in Mexico in that society--in a kind of upper-class society where women had very few options. We had this tacit agreement that I would go away to UC Berkeley for one year, and then I would move to Mexico.

I had ended up spending many summers in Mexico as I was growing up. And that was kind of an interesting experience for me, too, because it's such a culturally different environment. I had a boyfriend in Mexico at the time, too. The idea was everybody thought I should go to college a year and get it out of my system and then move to Mexico and marry this man and live happily ever after. [laughs]

Jacobson: And so what happened? [laughs]

Brand: What happened was I went away to Berkeley and I never went back either to Mexico or L.A. except to visit. The world opened up to me when I went away to Berkeley. All of a sudden the world was so much larger. I realized how much of a ghetto I had lived in as a child--how few experiences I had. It wasn't until I moved away and began to understand how much bigger the world is and how much more diverse the world was that--it just was an amazing time.

I was a hippie--had my green Harvard bag over my shoulders --and it was an amazing time. I was in college during the Free Speech Movement--FSM. I immediately went to the local college YMCA and worked there, signed up for a program, went up to a migrant labor camp that next summer, and helped to start a summer school program, and built a little library. I also began working on a federal project to train poor high school kids from Richmond to be tutors for young, elementary school kids.

Social and Political Life Changes--Marriage and Free Speech

Jacobson: You were talking about your work experiences at Berkeley.

Brand: Okay, well, I'll talk about the academic part briefly--the most interesting part to me was the political and social and just life-changing events. The first year of college I was pretty focussed on academics. And I actually was terrified. I realized my education had been so poor, I was afraid of flunking out of college the first year. I didn't come even close, but I was anxious about it, and studied just constantly, I was so scared. And it's funny, because when I talk with my husband, Steve [Brand], he was shocked that there was any work to be done! I mean, it was very different for him. But I worked very hard the first year and lived in a dorm and when I realized I was going to survive then I really could open my eyes and look more broadly at what was happening.

It was a very interesting political time. At that time, there were all the issues in Berkeley about integrating the schools, and bussing, and recall elections, and then there were the early years of the Vietnam War and the fight to unseat a Congressman, Jeffrey Cohelan and the Robert Scheer campaign to try and get that seat. He didn't make it, but almost did, and it led the way for Congressman Ron Dellums to eventually gain that congressional seat.

So there were a lot of really, really interesting things going on during my years at UC Berkeley. The Free Speech Movement was very pivotal in my life, though I wasn't one of the ones arrested because I was working on a federal project and I was afraid of jeopardizing the project. But Berkeley was a very significant time for me. I actually believe that growing up as I did, coming of age in the sixties, with the civil rights movement and so much happening led me and many in my generation to understand how much one individual could choose to do. I think there was a hopefulness that hasn't existed in many years in this country about being able to change the world and an excitement about one's role in doing something significant and all that, so it was a great and very defining time in my life.

Jacobson: When you were at Berkeley you decided to go into teaching?

Brand: Well, I didn't actually. I didn't have a clue of what I wanted to do during most of my school years. I was studying general social science--it was called social sciences field major. My key area of interest was cultural anthropology but I did a little of this and a little of that and it led me at the end of four years with a B.A. and not a clue about what the hell I was going to do with it. [laughter] I originally thought I was going to go into graduate school in social welfare, but tried

it briefly, and was just disgusted by it. I said, no, I can't do this [small laugh] and so I dropped out.

At the time, there was a program, an experimental program, and it was very small--it was called the graduate internship program. It was a way to get a teaching credential with basically very intense seminars all summer for one summer followed by a real job, combined with Saturday meetings all year with all the interns. People would get jobs in different districts and at the end of the year you'd have your credential and you were a teacher. I said, okay, I'd apply for that. If I got into that, I'd do it, and if not, I wasn't going to go into another formal education school. I was really sick of school and I wanted to be out in the world, but I did get into the program and became a teacher.

Jacobson: Now, what happened to your dream of becoming a concert pianist?

Brand: As I reached toward the end of high school, the world was getting larger, and music was getting squeezed smaller and smaller. I was feeling as though I'd been very insulated in that world. Though I've used my music--I've taught piano--even while I was a high school student, I had seven students to earn money--and eventually came back to teaching music--I realized that I wanted to do other things. And the chances that I could actually achieve becoming a pianist as a concert musician were so remote. I don't think I had that in me really, but more than that I was losing interest as other things in the world were getting more important to me. I took a little bit of music course work in college, but the courses that thrilled me were more in the social sciences.

I remember so vividly the course that provided my first introduction to civil rights issues and some of the early research studies that were done. One was where children were given dolls of different colors to play with, looking at the ways in which they dressed dolls depending upon their skin color and the things that children would say about dolls that were black as opposed to white--those were the two colors that were used. I began to understand what it meant to live in a world with discrimination. Of course the sit-ins were taking place, not only in the South, but the Auto Row sit-ins in response to discrimination in hiring in San Francisco, the HUAC hearings, the House Un-American Activities Committee was meeting and hosing down demonstrators. I mean, I was learning more about what it was to be a migrant farm laborer and a child of a migrant farm laborer. All these things were coming to bear and I was trying to develop a better understanding of the world and how it worked, how it was just and how it was unjust,

and what was my responsibility and my role in that. That's kind of what those years of college were very strongly about for me.

Jacobson: So where did you begin teaching?

Brand: I began teaching in San Francisco in a continuation high school. It was fabulous. It was a combination of kids who were thrown out of the main public school system--it was their last chance and they were mostly in and out of the juvenile justice system--mixed in with immigrant kids who didn't speak English and were learning it in order to become integrated into the mainstream. I haven't talked about my life of meeting Steve and how that all interfaced and I know we'll go back to that, but those years were with Steve. We taught together at a school called Opportunity High School. Although the first term we taught both categories of kids, our interest--our love--was more with kids who had been thrown out of the other schools and less with the immigrant kids because most the teachers liked those kids best because they were very well behaved. It was the other kids who weren't showing up to school, who were treated poorly, who had nothing--no motivation to come to school--that interested us.

Jacobson: Jackie, are you bilingual?

Brand: Well, I grew up as a young child understanding and speaking some Spanish, understanding but never really speaking a little bit of Yiddish, but as I grew up, my family didn't maintain the two languages in the home. There were always family members who didn't speak English, so to this day, I have a fairly good receptive understanding of Spanish and a very rudimentary ability to speak, but in a crunch I can step in. When I spent time in Mexico, for example, usually my relatives would all want to practice English so I wouldn't get very good at Spanish except, again, receptively. I don't think I have a great flair with languages. Probably another person with a flair would have become a lot more fluent than I ever became, but certainly I find Spanish a fairly comfortable language to understand.

Jacobson: Is there--let me get into how you met Steve. I take it that you met him while you were at Berkeley.

Brand: He wasn't at Berkeley. I met Steve because I got involved in the federal project that I referred to--this tutorial project called the Western Student Movement. Andy Truskier had started with Steve in L.A., and then Andy had moved up to Berkeley to create a chapter up here while Steve was in L.A. working in the south central L.A. area, developing a project there. I worked

quite a while on this project and there was a tutorial conference at UC Riverside (so UC Riverside existed). Andy sent me down to that conference to meet Steve, essentially. He said, "You're going to like Steve and you need to meet him."

He didn't know how right he was. It was really a love at first sight kind of thing. I just totally--we both just totally went crazy over each other and within a few weeks he had moved up. [laughs] And so it was a very, very intense thing and then after a year we got married, actually, and went into the graduate internship program together at UC Berkeley. We both applied and got accepted, went through this teacher training program, got hired at the same school, which was kind of unique because there had been--most schools did not want to hire two family members in the same school. By the second semester they agreed to let us team-teach. What they did was basically give us a huge shop room, and put the equivalent of two full-sized classes in there. We called it the Brand Suite. They basically said, "If you can entertain these kids, we don't care what you're doing."

An Individualized Approach to Education

Jacobson: The Brand Suite--s-u-i-t-e?

Brand: Yes. [laughter] It was a huge physical space and there were so many kids that were assigned--although these were kids who were truant more than not. And we would visit our kids very often in the Youth Guidance Center as they were arrested for this and that and the other--so the numbers of kids who were in school at one time were never that large. But we took this shop area and created an environment that hadn't really been done before. We created an audiotape, headphones section where kids could listen to stories because we began to--we're both trained to teach English and we realized we had kids who didn't read and so we became reading teachers. We also got to understand that we had some very bright kids who had never had the experience of enjoying a book because they struggled so much with the physical aspect of words--you know, figuring out words. They were word-by-word readers at best and very often non-readers or second grade level readers. We wanted them to have the pleasure of knowing what it was like to experience a beautiful piece of work.

Jacobson: What was the response?

Brand: It was incredible, which gave us the ability to do anything we wanted to do at that school because kids were coming to school for the first time. We did a very individualized program, today you'd call it an IEP [individual education program], but that didn't exist then. We did contracts--individual contracts--with each student. That's like an IEP with that individual, I mean, [laughter] but who knew. We brought in reading material that was relevant. In fact, some of it embarrasses me right now. I think some of it was real junk, but we wanted to motivate the kids to want to read. We arranged for the kids to get credit for coming to school. And when they were in jail, as they often were, we'd go to jail and bring them assignments so they wouldn't lose time or credit--so they would keep working while they were in jail. And we brought books, so many books, so that eventually kids began to ask us, "Did you use to work at the YGC?" Every time we bought books, paperback books, we bought them from our own salary because there was no budget. We'd stamp our name in it and the YGC just became full of books with our name on it, which pleased us.

Jacobson: What is the YGC?

Brand: Oh, Youth Guidance Center, sorry. That was the Juvenile Detention Center. So the Youth Guidance Center just became full of our books, they thought we must have worked there, which we never did, of course. But we were there a fair amount to see our kids, either to visit, or to bring assignments, and try and maintain the kind of tie and stability and connection and consistency, to suggest we were there with them. We were very devoted teachers and we loved our students and had a lot of respect for them, although one by one many of them died over the years. They often died in violent confrontations or by drugs. It was pretty scary to watch that whole thing happen because we saw that the system didn't work: these were bright kids who weren't learning and weren't achieving in a system and were finding other ways to achieve success by stealing, dealing drugs, and escaping the world through drugs. You could just see the effects of a poor-working social system.

We did that for a couple of years and then we had the opportunity to work at the administration office at the San Francisco Unified School District. I kind of marvel at it now. They brought us downtown for a year--a group of us--to design a new school based on what we had learned--to try and develop a school that would be more successful with the population they had been so unsuccessful with.

Jacobson: What year was this?

Brand: Gosh, well--first, before I think of the year let me rename it. The name of that first school wasn't Opportunity--Opportunity was the school we created. The first school we went to was called Samuel Gompers High School; that was the continuation school.

Okay, if I graduated--I would say it was '69, seventy-ish. Yes, it was before Michelle was born, so it was '68, '69. Yes, I must have started teaching at Opportunity around '67, and we designed and started Opportunity High School around '68 or '69, which was based, again, on a very individualized approach to education for kids and also designed to develop curriculum based on student interest. I think it was a pretty successful model.

Jacobson: And then what happened?

Brand: I ended up leaving to work more on a part-time basis because I was having this desire to have children. Steve stayed at Opportunity High School longer than I did and then eventually moved into some other areas as well. It was a wonderful training ground for both of us in everything that we did, because when you work with a group of students who are so unvalued and you begin to peel away all that stuff and understand the potential of people and the need to learn from people about what their own needs are--I think I learned a lot of the lessons that held me in good stead as a parent and as an educator and as an activist over the years. It was one of these cases where the existing system doesn't work, so you could just say, "Oh, too bad," or you could try and change the system. It was one of our early forays in our professional capacities into questioning the way in which the system worked and redefining it.

Jacobson: How was the school funded?

Brand: It was funded as a public school as a part of the school district. I don't remember so much about it because I don't remember saying, "We need to build this school; how do we find the funds?" It was more, "We're going to be creating a new school; you guys seem to be interested in this population, would you like to work with us on designing some curriculum and developing a plan?" And it was just one of these great opportunities that fell into our laps. We didn't really have to create it ourselves, or find the impetus to fund it. It was part of the public school system and approved through the school board and then created.

I don't know where it is today. Eventually, the principal that came to that school was very close to a figure you might remember if you were here at that time--Jim Jones--and that whole Guyana tragedy. Many of the kids from that school--not when I was there, but a few years later--died in that horror. Many of the kids that we taught were very attracted by his philosophy. I was out of that picture for several years before that happened but--and I don't know really what became of that school--whether it still exists or not, as an alternative school. Alternative schools have had their periods of repute and ill repute around the country.

Birth of Michelle, 1970; Becoming a Role Model for Teenage Mothers

Brand: I moved from that environment into working with pregnant minors in special centers. When young women would get pregnant they would be taken out of the public school system and put in these special centers to continue their education. I had gotten more and more interested in reading and had been teaching reading, so I became the reading teacher for the pregnant minors program. I went to a program in Hunter's Point and in various parts of San Francisco--and I loved it. It was a wonderful job. I did that for about six years.

As the kids had their babies we had a little nursery for them, so I could also have a baby and bring my baby in and model some behavior as well. Also it was a great environment in which to teach reading because I used as my texts materials about pregnancy and child development. The young women were very motivated to learn about that. They also went through a period during their pregnancy of expressing the hope that their kid's life would be better and different than their own. It was a wonderful working environment to be in, and sad, too. There were some very, very sad situations of children who were raped and or had been put on the street to prostitute to support their family. They were also quite poor and so it had a lot of sadness, but it was an interesting time for me. I enjoyed that work a lot.

They found the fact that I was breast-feeding to be weird, too. They wanted--and I think my mother was this way, too--it was sort of a lower class idea that when you're so poor you wanted to be able to afford formula, never mind what they say is better for your baby. So I think they found it kind of odd that I could be nursing and teaching at the same time. I

thought that was a really good, good experience to have and it was good for them, as well.

Jacobson: I'm curious. Was that at the time when breast-feeding was still not in vogue, before it started to become popular again?

Brand: That's right, it was still a little countercultural in and of itself. People didn't really recognize and acknowledge the value and importance of it. It was a great teaching situation because I could continue teaching and feel like I was doing work that I found interesting. But I taught on a part-time basis and brought Michelle, my baby, with me. It was a great thing for me at that point in my life to be able to teach and have my child with me--the best of both worlds.

Jacobson: When was Michelle born?

Brand: December of '70, so almost '71--December 16, 1970. She was born on her grandfather's birthday, so I took care of his gift forever. [laughter]

Jacobson: And were you living in Berkeley at the time?

Brand: Yes. In fact, if we hadn't been living in Berkeley we would have moved to Berkeley once I had kids because that was the only integrated school district around and it just seemed to us that that was the place to raise a kid--in Berkeley--and to put a child in school.

Jacobson: When you talk about integrated you mean racially?

Brand: Racial integration is what I'm talking about, that's right. There was not, at that point, any people with disabilities in the entire world through my eyes. At least not many.

Jacobson: So you never knew any people with disabilities?

Brand: Virtually none. I had an aunt with spina bifida. And we had a neighbor at one point in one of the zillions of places we lived where there was a man with mental retardation. I remember a little bit about him. I had been told when you see a person with a disability you don't look, you don't stare, and you definitely don't ask questions, so I had sort of the standard AB (able-bodied) training on disability. [laughter] And you know, I'm trying to connect the independent living movement in Berkeley--I'm trying to think when Ed [Roberts] was at UC. What year did he start there?

Jacobson: I think in the mid-sixties.

Brand: In the mid-sixties--not the mid-seventies. Oh, no, no, of course not. By the mid-seventies, I was working at CIL. [laughs] So yes, that didn't exist for me. No--virtually at all.

Birth of Judith (Shoshana), 1974

Jacobson: Jackie, how old was Michelle when you gave birth to Judith?

Brand: She was just under four years old--three years and eleven months. Judith was born November 18, 1974, and Judith was born as Shoshana Brand.

Jacobson: And she was not born with a disability?

Brand: That's right. She was born with a heart defect, so she was born with some medical problems, but she was not born with a disability. She was born with a very severe heart defect. She was born by Cesarean section because she was a repeat Cesarean. In those days--I don't think they do this any more, but Michelle had been a very long labor and eventually a C-section. In those days, once you had one C-section all your follow-up babies were done by C-section and so she was a planned birth by C-section and she was put into intensive care right away. I think her Apgar scores were not really good right away, and although she had a very serious heart defect, they didn't diagnose it. They could hear a murmur, but most heart murmurs are what they call innocent heart murmurs and mean nothing, so although we had been in the hospital for six days--that's because I was recovering from a C-section and that's how long they kept us in those days. We went home from the hospital with the understanding that I would come back--it was Kaiser Oakland--that I would come back to meet with the pediatric cardiologist just to confirm that everything was okay with her heart. So we had her home one night, then we took her into the pediatric cardiologist who examined her and determined she should be rushed back to the hospital immediately.

II JUDITH'S DISABILITY, SEARCH FOR RESOURCES, MEETING JUDY HEUMANN, QUESTIONING EXISTING SYSTEMS

Judith's Heart Defect

Jacobson: Jackie, you were talking about when you first found out Shoshana (Judith) had a heart problem.

Brand: The cardiologist confirmed there were some serious problems and we were rushed to the UC San Francisco hospital where she underwent what's called cardiac catheterization, a procedure to determine the extent of her heart defect.

She was diagnosed with what's called Tetralogy of Fallot, a very serious heart defect that has several parts--actually four parts: tetra. Fallot is the name of the guy who identified it, so it was named after him. And just in layman's language, she was a blue baby. In retrospect now that I know about cyanosis, or blueness, I can't believe that the medical staff at the birth didn't recognize that right away. They should never have released her, really.

However, the seriousness of her defects were such that they didn't want to have to try and attempt a correction at her young age. They wanted to see if she could remain stable enough to grow more before surgery. They wanted her heart to grow a little bit before they attempted a correction. They didn't have much experience--much success--yet in correcting this defect. They had brought some kids through, but not very many.

So after she spent several weeks in the hospital, we went home where we were told to not to let her out of our sight because if she went into what was called a cyanotic spell--began to have trouble breathing, whatever--we needed to rush her in and do that procedure. So she was medically a pretty

fragile little thing--pretty weak and breathed heavily--but she grew and she reached all those good milestones, which was encouraging to us. We would have expected her to be a little slower in doing stuff, but she reached her milestones all on target.

Then when she was about eight months of age she got to that point where they couldn't wait any longer, so they did another procedure--hospitalized her and did another cardiac catheterization--and then spent several days arguing amongst themselves how to proceed--what was her best chance of survival.

There were two ways to go. One was to attempt a total correction of her heart right at that time. The other was to attempt a bypass procedure: to take a vein from her arm to hook up to her heart to give her an alternative path to get oxygenated blood flowing. It would have given her time to get older so she would have more strength and a larger heart to work on. They would have a better chance of success that way. So they hemmed and hawed about that for several days and in the end decided what they needed to do was the bypass procedure just to ameliorate the situation, not to attempt a correction. They just didn't think she could survive a correction.

At eight months of age, they did this surgery called a Blaylock Tausig Shunt--put in a shunt. And she stopped breathing on the table. They pulled her back, but she sustained brain damage and her disabilities come from that surgery. The results of the brain damage was something that came to us over hours, not immediately. They essentially did the surgery--the shunt didn't work. It leaked all over the place, they had to undo it, stabilize her, and redo it, so it was many hours of surgery. It's kind of remarkable that they actually brought her through it. I was sure that she had died and they just didn't have the guts to come out and tell us, but [sigh] it wasn't that.

So as she began to come out of the anesthesia, we could see her eyes were averted way high up and she cried and screamed and never stopped. She was stiff, very stiff. That's kind of where the medical establishment gets stuck: "Well, gee whiz, I don't know, take her home and love her." [laughs]

Family Prepares for Judith's Surgery

Jacobson: I wanted to ask--during those months before the surgery, how did you and Steve deal with it?

Brand: Well, we did go through some counseling to try and think it through and cope with the uncertainty. It was very difficult. I had a lot of nightmares. I'd go to the cardiologists and they'd say she has a 10 percent chance of making it through surgery now; and now she's a little older, I think she probably has a 20 percent chance. I would have nightmares of nine babies being killed and one being left. And was that one mine? And then eight babies being killed--and it was very hard.

And then there was the whole issue of Michelle and how she could understand it--what to tell her and what not to tell her, how to handle it with her. That was difficult too, because it's very hard to get good advice. I went to Michelle and Judith's pediatrician at the time, who's a very renowned pediatrician in Berkeley. Everybody loves him dearly--and I loved him dearly when he was Michelle's pediatrician. I asked, "You know, Michelle's four. What can she understand and what should I tell her? How should we handle it?" He basically said, "What's the matter with you? What kind of a mother are you? You don't tell your four-year-old anything, you just handle it."

Which was very bad advice, but Michelle taught us that was bad advice pretty quickly because not too long after that--I will never forget this--she came to me with a picture she had made and she showed me and she says, "Look Mommy, I made a picture of Daddy." And I said, "Well, what's that big black thing in the middle of his body?" She said, "Oh, he has a broken heart and he's going to die." I realized that she had put something together about the person she cared most about in this world--not this screaming little baby, but her father--and had decided that he was going to die because he had a broken heart. So we sat down together, and that's when I understood we had to explain the whole thing to her, simply, but directly. It was the greatest relief in the world to her. She only could care so much about this new little baby anyway [laughs] and her dad was okay. I learned a major lesson about honesty and children that I actually tried to talk to my pediatrician about, but he didn't respond. I left that pediatrician and went to somebody else.

It was tough worrying about whether we were preparing for a life or for a death, and how to do it. I worried about it in

the earliest days mostly through Michelle's eyes. What would be with this infant was going to be, and I would do everything possible, but how do we handle it with her older sister?

As Judith--as Shoshana--got older and we had to worry about issues like medical personnel saving her life, or thinking that they were going to do us a favor by not saving her life, we began to get more into how do we convey to the medical world that we value our daughter. How do we let them know that it's okay if she can't do certain things--we don't give a damn about that? We wanted them to save her life and that became a big issue because she had--this first surgery only bought us a little time. She needed a repair still, and that came at age three and a half.

Jacobson: Now, did you feel that way right after her first surgery?

Brand: After her first surgery I was so amazed that she was alive, I was so thrilled! The doctors were all so depressed and I couldn't understand it. It was so strange to me. I had buried her in my mind, I had spent the day cursing them and burying her, and thinking through how I was going to explain it to Michelle, and how life was going to go on and then they came back and she was alive! So it was--I was joyous, I mean, that was my first reaction. It was just unbelievable that this child of mine was alive.

Then I began to see she was a different child; she was a new child and there was some work for me to do--for us to do as a family--to welcome and know this new child who couldn't see or move, and appeared not to want to be touched. She cried and screamed when anyone picked her up. That was a big thing for me, which is, this is not possible: you can't not want to be touched. So we had to fight this little thing, this little child, to love her and hold her, despite her screaming and carrying on when we came near her or when we touched her. It was a very difficult and sad and painful time trying to figure this out.

Very quickly we began to look for outside resources. They weren't in the medical world. We needed to find other resources and we figured there had to be places. You know, that's when you think, "How could we have managed to be lucky enough to choose the one place in the entire world where there could be answers--to live in Berkeley. Imagine living anyplace else in the world!" [laughter] So that was just almost immediately so remarkable that I would have gone anyplace in the world but I didn't have to. I was living in a world that was going to help me learn some things.

Remarkable Disability Resources of Berkeley; Connecting with CIL

Jacobson: Where did you begin to look for resources?

Brand: One of the earliest things that we did--we did a few things. I don't know quite how we found out that there was a regional center system, but we learned that there was an agency to work through, so we immediately--well, and we did go to a pediatrician who said, "This child needs infant stimulation," and so we went applying to programs that provided infant stimulation. There was an ARC--Association of Retarded Citizens--that had a preschool program. It had waiting lists. Regional Center had a waiting list. That was shocking. We actually had to threaten a lawsuit way back then because they were saying to us, "She needs certain services and we're not going to give them to her."

We also started reading about and learning about different therapeutic interventions. We went to CIL, but it's not easy to go to CIL as a parent, so I had to get to be an employee before I could get any credibility there.

Jacobson: [laughs]

Brand: So I did that pretty quickly. I went to work at CIL. [laughs] I began to just meet people and talk to people. Very early on I spent a weekend as an attendant to Judy Heumann--I just wanted to get inside her world and understand what it is like to be an adult with a disability. I didn't know--had no experience--so I was her attendant for a conference in Santa Cruz. And I found out about--and went to workshops and sessions everywhere! Our life just became very singularly connected to meeting people and learning what we could.

Jacobson: I would like to come back--you said that a pediatrician told you that you need infant stimulation. How did you find that pediatrician?

Brand: I think I found that pediatrician through the regional center system.

Jacobson: When the hospital discharged Judith after her surgery were you given any resources at all?

Brand: They brought in a neurologist. That's when I actually first began to hate neurologists. [laughter] I'll never forget what's-his-name. I've blocked his name, but his face is

ingrained. His words to me were, "Take her home and love her." That was it.

I don't know how or from whom I learned about the regional center system, but part of the application process was a visit with their physician. And the physician recommended infant stimulation, and because you couldn't afford these programs--they were very, very expensive--it had to be funded by regional center. Nobody went as a private client. I guess there may have been an occasional very wealthy person who could do it. But basically it made me crazy because they said, "Here's what she needs and that's what she can't have because she's going to be on a waiting list and she won't get off the waiting list until she's no longer an infant." And I said, "Well, how do you do infant stimulation if, when she's infant, you can't get stimulation?" [laughs]

We did a lot of things on our own. For example, she had what's called cortical blindness--that's the vision problem she was left with--it was neurologic brain damage, not the mechanical function of her eyes. Now cortical blindness was not well understood yet; they were still doing some early studies about that, but there was one guy in San Francisco, a pediatric ophthalmologist who was studying children with cortical blindness, and we found him and he said, "You know, she's going to probably recover some vision. We don't know how much, we don't really know how functional it will be, but there will be changes. And there will be changes over a long period of time and so, give her all the visual stimulation that you can." So we got that recommendation.

How we found Creig Hoyt, the pediatric ophthalmologist, at that point--I just don't know how we did the research. There was no Internet, [laughs] but I think we just talked with a lot of people. In fact, there were a lot of people with expertise.

I started immediately going to a parent support group that was very helpful.

Unique Parental View of Disability; Support of 504 Demonstration

Jacobson: Who offered it?

Brand: It was the ARC that offered it and, you know I grew to the point of having tremendous differences with them over their

philosophy. I began to see that they viewed parents as a pathologic unit themselves, by virtue of having a child with a disability. There was some pathology that was implied on the parents and their whole theories about grieving and denial and whatever the categories were which I didn't buy at all.

But there were other parents there who were further down the road and who were dealing with issues and knew some things. Mary Picchi was in that first parent group and she had a son named John with very severe disabilities. And there were people that turned out to become the first parents to be on the board of DCCG when that got started, that I met in this very early time.

Jacobson: What is DCCG? [laughter]

Brand: Disabled Children's Computer Group--sorry, yes. But anyway, so that peer support group was really very important for a very short time, but definitely for a period of time. I mean, I got support, but I also learned about some of the typical ways that parents experience disability and that was troubling to me.

That really defined a lot of things for me, too. For example, there were parents who did the religious number: this is God's--God has given you what God believes you can do. But there were people who were coping with things in very different ways.

I began to realize, too, that I had a very different idea--the first thing I wanted to know was--you know, you have children and you think about their future--and I wanted to run down and meet people and say, "So what's it like to be a grown-up with a disability? What's it like to be in the schools with a disability?" I found most of the parents thought that once they did this therapy the disability would sort of go away or something, or, "Don't ask me to think about it." And I'm thinking there's a whole world here that I never knew existed. I have all this opportunity--my daughter could have a mentor, could meet people having lives. I didn't know anything about that life and, thank God, I get to learn. And she has to be exposed.

So there was for me a tremendous focus on connecting with people. Some of my earliest friends were people like Corbett O'Toole. She was extremely pivotal in my life. And Judi Rogers at a certain point; Steve Hofmann, very important early on to me--there were other people later. I'm trying to think who some of the earliest influences were in her life. Well, those were some of the key people.

So the parent group was very important and also troubling to me very early on. There's a very interesting story that's definitely out of context, but it relates to this story, so I'll tell it and maybe it'll fit later on. During the 504 sit-ins--let's see, do you remember what year that was?

Jacobson: '75?

Brand: No, no, it was after that.

Jacobson: '76.

Brand: Was it that? Maybe '76. [April 1977] But anyway, during that time, it turned out that we were out of town when they started and when we got back, and learned that this 504 sit-in was taking place at the federal building, the four of us went over to the federal building. We didn't actually move in--but I went to the door and people would come out and you could talk with people or you could go in. And Judy [Heumann] came out and said, "What the hell are you doing out there!" I said, "Well, we just got into town. What do you need?" And she said, "Get parents out! Get a lot of parents to bring their kids and to demonstrate out front. That'll create press." So I said, "Great, I know all those people."

I got on the phone and called parents. One after another they said to me, "This is not our issue, that's those people. That's not our issue." And oh, my God, that was just so amazing to me to realize that! And I kept saying, "You have a child who's going to become a grown-up. You have a disabled child who will grow up and become an adult with a disability. This is your issue." They'd say, "I can't think about that, my kid isn't going to be like them," or something like that--just total inability to imagine or identify.

I hope that attitude has changed today. I bet there are families who have young children with disabilities who have a different view of the world, I hope, as a result of the movement. I hope that's changed some.

Jacobson: I think it has changed some, but I still see that gap--

Brand: Yes, I'm not surprised. There were a couple of parents--Bev Bertaina was one of those parents--a few people who understood this was all of our issues and came out. But most parents of young children wanted nothing to do with it, didn't understand it, didn't want to understand it, didn't want to--I mean, to me, my children were seeing their history--our history. It was so significant and so important.

Anyway, parent support groups only took me so far, because I just didn't have either the ease of mind to think of the issues in the same way most families did, or just had a different view from many early on.

Memorable First Meeting with Judy Heumann

Jacobson: Do you remember what year you went to work at CIL?

Brand: I have to look that up, because it was around--I went to work around the KIDS Project. Let's see, it was called Keys to Introducing Disability in Schools. I think the acronym's words may have changed over the years, but at that point it was a project where we were developing curriculum, testing it, piloting it in schools in Berkeley and Oakland. The program was designed to prepare students and teachers for inclusion, then called mainstreaming, by introducing them to people with disabilities. So we were both developing a curriculum, hiring people to work in doing it, and implementing it ourselves to try and learn from it.

Jacobson: And was that after you had been doing attendant work for Judy Heumann.

Brand: Yes, it must have been. Now, how I met Judy. I went to a meeting she held and I had a major argument with her at my local school. This is before Shoshana was in the schools and she said to me, actually to the group of us there: "If I were a parent getting ready to send my child that had a disability to school, what I would do, and what you should do, is drop your kid off at the school and say I'll be back at two o'clock or whenever school is over and leave."

Jacobson: [laughs]

Brand: And I said, "You're not a parent and I couldn't do that." We had that discussion/disagreement. You know, she was like out there.

Jacobson: [laughs] Yes.

Brand: That was amazing to me, and wrong to me. In retrospect, I'm not sure she wasn't right. It was very provocative and she did the right thing by saying it. I think that that's when I must have met her. That's the first recollection I have of her.

We became personal friends. I know she came to the house because she got to know Steve and Michelle and Judith--everybody. And then there was the 504 stuff.

Jacobson: Jackie, did you think when she said that, she was trying to be provocative, or did you think she really meant what--

Brand: Of course you have to ask her, but as I look at parents, in general, of new babies I think someone's got to kick butt. And somebody else--actually, a nondisabled person was the very first person to kick my butt, and I'll never forget it and I'll thank her for life. I'll tell you that story in a minute, but I imagine Judy Heumann understood that and knew that you needed to push things. I think she also believed it, too, but I think she must have seen such a gap between what she believed and the way parents were behaving.

I have to say, in the parent movement at that time, because one of the other groups of people I turned to in those early years were older parents of kids with disabilities, saying, "Well, how did you make it through?" And at that time they had just built a special school for kids with mental retardation at the Martin Luther King site, so these are families who'd had kids out of school entirely and had taken the revolutionary step of building a segregated school for their kids. That was a big step in an important direction to fight for their kids' right to an education and we all came along--us upstarts--and said, "Forget that, we don't want to be in your school, we want to be in our neighborhood school." That's what Judy was saying, basically, so that was a big leap from where the parent movement had existed as I knew it.

My first thought was that's--you know, that I can see parents wanting to create a beautiful protected, insulated environment for their [in small voice] poor little disabled kids where they get taken care of forever and have sixteen aides per kid and like that. [normal] That's a very parental, over-protective mode. And that's, if I can imagine, what Judy was reacting to.

I learned that in many ways from many people: Steve Hofmann taught me that Judith would never attempt to communicate really until she didn't have me to intervene on her behalf.

The Special Education Monster ##

Brand: Anyway, parents had moved into this very segregated thing. We had created this monster, I think, called special education. We'd convinced all regular educators that they had no skills to work with kids with disabilities and that they had to be in special places and special environments. My greatest fear was that people wouldn't touch my kid--that they'd be afraid to touch her--for fear that she would break. And because she had significant disabilities and, as a little one, looked so fragile--she was, you know, little and tiny and thin--I was so worried that people would treat her as essentially untouchable. In fact, I have to tell you, in elementary school one of the happiest days I remember is when people called to tell me to come to school. They were terrified she had fallen out of the swing and kind of got all bruised up and everything. And I said, "She was in a swing!" And I was so happy.

Jacobson: [laughs]

Brand: Again, they thought I was nuts, but you know, that was my greatest--my greatest fear wasn't that she'd fall out of a swing, but that she'd never sit in a swing.

Jacobson: Oh, yes.

Brand: Not that people would push her around, but that people wouldn't! --You know, interact physically and all that stuff. The therapist would say, "You've got to hold her in this way," turning all interactions into "interventions." And I used to say, "Well, you've got to hold her so you don't hurt your back, that's what you've got to do. And everything else is like optional and here's some strategies but you've got to figure out what works for your body, so that, you know, if you're running and you need to grab her, you can grab her and not worry." So I always had a very different attitude toward it than [sigh] special education.

I was at odds with a lot of people through the years, I realize. [laughter] I once screamed at someone, "I used to be a very nice person!" [laughter] You get into this bind working with the special education system.

A Kick in the Butt

Jacobson: I know, I know. Tell me who kicked your butt.

Brand: She was a pretty unpleasant lady. Man! Clara Lee Edgars was her name. I went to her workshop where she was working on therapeutic interventions for kids with disabilities and her revolutionary idea was that it's less valuable for a child to lie there and be manipulated than for a child to gain control of her body parts to the degree she could.

You went to the first session and you brought your child and they would use various kids to demonstrate various things and put the kids in weird positions and it would be scary and they'd cry a lot and stuff. But it was designed to encourage young children to take charge of their own bodies. Anyway, my little Shoshana was sitting on my lap, cute little thing, and Dr. Edgars just walked up to me and said, "She's really cute. I want you to picture her eighteen years from now, lying on your lap like that. She won't be so cute. You better get to work, or that's what you've got in store." And that was it. I dropped everything, we went to southern California, went through training with this woman, and we began a process of therapeutic intervention which was highly suspect in the therapeutic community but it made philosophical sense to me. It was about Judith finding her body and controlling it, even at this tiny, tiny age. And that felt intuitively right to me.

Jacobson: And how old was she?

Brand: She had to have been about a year, maybe. She was eight months old when she had the surgery where she became disabled and before she was a year old we had her involved in different therapies. We did a lot of research. There was a therapy that some people were doing at that time that we rejected called Doman-Delacado. Do you remember anything about that?

Jacobson: Vaguely.

Brand: Oh, man, this was therapy by guilt--ten, twelve hours a day. You'd give up everything in your life except moving body parts. And it takes seventy zillion people to coordinate the therapy.

Jacobson: Yes, it's patterning?

Brand: Yes, patterning, that's right. Well, there were families who did that.

That seemed wrong to me. One, it was like destroying the family and Michelle, and second of all, destroying Shoshana as if all she was was a body to be patterned as opposed to a child, a baby, to grow and learn. I just couldn't stop everything and just do this. It made no sense to me.

But the therapy taught by Dr. Edgars [laughs] just made sense to me. Its idea was: this is your body and your life and the sooner you get the control over it to the degree you can, the better off you're going to be. It was about relaxation techniques, finding and isolating body parts, being able to move, and being able to find and relax a body part. It was much more active: Judith had to do the work instead of lying passively while others moved her body around.

She worked her butt off for many years doing this stuff and I think it was very important to her. She built a close relationship with the therapist she worked with, who was a student in the very class I went to, who was willing to work with her, because there was no one trained in this technique. I knew it had to not be me. I wanted to be mother and I was going to have plenty to deal with, I didn't want to also be therapist. So we did that for a number of years.

Clara Lee Edgars' approach said you could sit around and baby your baby or baby yourself or feel sorry for yourself, or feel sorry for anybody, or you could just get to work. And getting to work always appealed to me as the better mode for anything I've wanted to do in my life and seemed right for Jude too, so we began a very serious amount of work on that.

Eventually, she got resistant and it looked like we needed another way to go which was that she needed to find her own way to maintain her health and happiness in ways that she would choose, so we eventually gave up therapy for swimming. She became and she still does a lot of swimming and that's what her main therapy is, along with her own exercise program that she's responsible for. She needs people to help her with it, but it's her responsibility and she has done a great job with that.

Questioning Therapy Model

Jacobson: How old was she when she became resistant?

Brand: When she became resistant?

Jacobson: Yes.

Brand: I could see it happening over a period of time; it didn't just happen. I'd have to go back to my records to try and figure out--because she was extremely strong in her reactions to a lot of stuff.

For example, we still lived on Yosemite Road in Berkeley. She was a young child using a walker, but she wasn't independent on a walker. She couldn't really stay up very long. One day she was really angry at me. I'll never forget this. [laughs] I can't remember what it was about but she wanted to run away from home and she didn't have her chair; she couldn't maneuver herself. The only mobility she had was the walker, but couldn't handle it without support. She told me to let go of her, that she was running away. I knew that she'd fall right down if I let go, but I knew I had to. It was a very important moment for both of us. She had to have the opportunity to make a decision, even though she couldn't carry it out.

I mean, that's one of the very big issues in parenting a child with physical disabilities, which is that separation and allowing her to have integrity of who she is separate from who you are. I think it took her longer than it takes somebody else to understand where she ends and her parents begin because of all the physical support she needed, and so I think it was very important to be aware of that.

Jacobson: I think that's very common for a lot of disabled kids, not knowing where they end and their parents begin. They don't get a real definition of who they are.

Brand: Yes. And therapy is part of the problem of that, too.

Jacobson: Yes.

Brand: So there's a whole negative aspect to this whole therapeutic intervention that I had to come to grips with. I realized that when I talked to adults--there was a time when I was asking a lot of people this question--they all told me they had thought they were all doing therapy because then they were going to become nondisabled like their family members.

Jacobson: Yes. We were all going to walk.

Brand: Right, exactly. And just a funny remark on the other end--Michelle once asked me, and she was pretty old, "Who was my therapist who taught me to walk?" [laughter] She didn't know

that people actually learned without therapists! "Now, how did I learn to crawl? Did Kate work with me, too?" That was really funny.

Yes, but that was part of my growing concern about too much therapy, which is that there is a message here that says: "You're not okay and we're trying to make you as close to us as possible." You're never going to do it, so you're always going to fail. And this part of therapy is for the birds because it's really rejecting the more important things about who you are and what your value is and how you function and all of that. I became extremely concerned about that pretty early on, too, so I'm not sure I can identify what things Jude did that helped me to learn that. I'm sure that's where I learned it--where else would I have learned that?

As we grew to that understanding trying to come up with other ways--we stopped speech therapy for the same reason, and she started taking singing lessons instead. It was the same deal. It's at a certain point the "R" is not going to be "rrr" you know? You can go to therapy as long as you like, [laughter] but it's not going to happen.

At a certain point you say, "Okay, now go out and do what you need to do in the world." And she loved music--Judith is very musical. Well, Steve is musical, I'm musical, Michelle--we're all musical, and her voice was going to be her best instrument for exploring and developing that musicality. For many reasons singing seemed like a much smarter idea than speech therapy and so that's what we did. She was still in elementary school. I know that because I remember her first singing teacher, Dan. She was at Castro School in El Cerrito, so it must have been fifth, sixth grade for her. She was a little on the older end of those grades, so she was probably maybe twelve or something when that started to happen. And swimming was good for breath control too. Then she got into drama--that all led to drama and she did a lot of dramatic stuff--but yes, speech therapy just like physical therapy tended to focus on the things that we call failures, really.

Discussion of Realistic Expectations

Jacobson: I know some parents now who get very upset because they feel their child is in denial.

Brand: Their child is in denial?

Jacobson: Yes. For example, I know a little boy, about ten years old, he--

Brand: About how old? Ten?

Jacobson: Yes. He has cerebral palsy, but very minimally--he walks and he wears braces--and his father is worried the son always talks about wanting to be a basketball player or he brags about being an expert on riding a bicycle. I keep thinking that's great! [laughs]

Brand: I know. Like, so the problem is what? [laughs]

Jacobson: That's right. I mean I wanted to be a ballerina when I grew up, and at some point I got it that I probably was never going to be a ballerina--

Brand: Or president of the United States. Yes, that's right. Yes, I think the problem is on the other end when you think you can't be anything. Yes, I mean, at ten!

Jacobson: So I wonder if you ever thought that by letting Judith take swimming, singing, and drama lessons that you were afraid of giving her false hopes? I hear that fear from a lot of parents.

Brand: Well, my general philosophical belief is the biggest problems in the world are ones of low expectations, not high expectations and that in a very loving protective way parents tend to do that. I have on many occasions spoken to this idea of dealing with people telling me to have realistic expectations. I just don't think realistic expectations are all they're cracked up to be. My whole life has been questioning realistic expectations and I hope my kids, both my kids, will also question those things.

After saying that, I also realize there was a point with Judith when she used to say, "When I grow up, I'm going to be a bus driver." She used to ride a yellow school bus, and there was a year when she had a bus driver she loved so much. But she has very little vision, and at a certain point I said, "You know, Jude, people who drive buses have to have very good vision. You're not likely to be a bus driver. You might very well own a bus company or you might this or that and you're going to get around this way or that way, but seeing the road is a requirement of that job." And that really upset her and she still will refer to that time when I told her that, so it was very momentous to her.

Maybe it was the wrong thing to say. I'm not sure it was the right thing to say, but it felt like such a--I don't think it was denial, but I was just trying to make a connection for her that she hadn't made. She didn't have the vision to even understand what it meant, she just didn't understand. I think my intent was to say, "You know what? That's a talent that takes a lot of vision. There are a zillion things in the world that require little or no vision, or there are a zillion other ways to accomplish something." I did do that, but in terms of achieving--and she wanted to be an actress, and she wanted, you know, she still wants to be a mystery writer, and she wants to this and that; she still has all sorts of great dreams.

I don't know what she's going to be when she grows up, but I think we do a terrible disservice to any of our kids. I don't really think it's disability related, except that parents of kids with disabilities are really endowed with low expectations for their kids and I know they get it from the world. They really need to not--they need to have high expectations of their kids and know that their kids are going to work it through. And that boy's either going to, you know, [laughs] do a Forrest Gump and become a basketball player, or he's going to do adapted basketball, or he's going to find something else to be great at, but right now, that's his dream.

I don't have a problem with it, really. I feel like we all have surprises in our life. We all find ourselves in interesting and unusual places that we never planned for. We need to have dreams and visions and strategies. There are moments when we have to come to grips with realities--and we do, we have to. We just need the strength of character to face life. I don't think it's all that helpful to disabuse kids of dreams--it was unrealistic for me to think about being a concert pianist. I just don't agree with discouraging dreams and hopes.

Jacobson: I think this will be a good time to stop.

Brand: Me too, I'm ready. This is good.

III WORK AT CIL'S KIDS PROJECT, JUDITH'S PRESCHOOL THROUGH MIDDLE SCHOOL EDUCATION, SIBLING EQUITY

[Interview 2: September 7, 1998] ##

A CIL Satellite--KIDS Project, 1979

Jacobson: Jackie, would you clarify something before we go on and talk about your work at CIL? When we talked about your youngest daughter, you've used the name Shoshana, but you have also called her Judith. Can you clarify that and tell us which name you would prefer to use?

Brand: Yes, Judith. Okay, my second daughter was born Shoshana Brand; that was what we named her. She chose to change her name and didn't legally do it, but for all intents and purposes is identified now as Judith Brand. She did that when she was about eighteen years old and so many people only know her now as Judith Brand. People who knew her as a child, know her as Shoshana. For purposes of this interview, I'll call her Judith because that's her preferred name.

Jacobson: Good. Now Jackie, could you tell me how you began working at CIL?

Brand: [laughter] Okay. Actually, it's a tough question you asked because I'm trying to remember exactly how I got to be working there, but I'll tell you the general answer and then I'll think a little bit more about the specific answer and I can come back and try and recall more. But once Judith became disabled when she was eight months old, I started checking out resources that existed in the community. And the premier place in the world, really, was Center for Independent Living, so I found myself going up there and trying to find out what was going on, what I could learn, and so on.

I actually found it fairly unfriendly to parents, in general. I was surprised to find that there weren't things for parents to come to and to learn or things for young kids to attend--to get mentoring, or anything like that. None of that existed, but I learned, somehow, about this federal project that had been funded and applied for it. I can't remember the details--I'm going to have to go back to Corbett O'Toole for the details on that because I worked with Corbett. I believe it was my friendship with Corbett that led to my work at the KIDS Project.

Jacobson: When was that?

Brand: It was 1979. It was after the law had passed guaranteeing a public education for children with disabilities. That had happened in '74, and it had language like "least restrictive environment" in there. But there wasn't really anything to speak of that was actually taking place that approximated a least restricted environment and so the idea of this project was to begin to prepare teachers and kids for what we called mainstreaming at that time.

Jacobson: What did you do for the project?

Brand: I worked with a small group. There were about six of us--let's see, Corbett O'Toole, Lynn Fingerman, Steve Guest, Judi Rogers, and myself, and one or two other people. I was writing curriculum and delivering training in the public schools in Berkeley and Oakland at the elementary school level--K-3 level.

Jacobson: What was the project called?

Brand: It was called the KIDS Project. [laughter] Thanks for asking. Keys to Introducing Disability in Schools. The idea was to develop curriculum and then to bring in kids and adults with disabilities as consultants to deliver that curriculum and to work with a classroom of kids. We felt that the easiest way to get to the teachers, which was our real goal, was to get to the kids or to talk to the kids. We believed that the questions the kids would ask about disability were the same questions the teachers wanted to ask but were too shy to ask, so through the kids we felt we could open up the dialogue around disability. It was not designed so much to teach people about what a disability was, as it was to create an environment for interaction of people with and without disabilities. It was designed then to create a natural progression of understanding, generated from questions that might come up about disabilities or how people might do things in a different way--whatever. It was just a very natural or organic way to introduce kids and

teachers who had no experience with kids or adults with disabilities with that experience.

Jacobson: Was this in the Berkeley schools?

Brand: We did the initial pilot in Berkeley and in Oakland--we went to some schools in Oakland. Over the course of that project I don't know how many schools actually had this kind of training; I wasn't with the project all that long. But as we were piloting it and learning it, it was in Berkeley and some Oakland schools--all K-3.

Jacobson: Jackie, how did KIDS get connected with public schools?

Brand: How did KIDS get connected? Meaning what?

Jacobson: Meaning, what approach did you use to get the schools to let you come in?

Brand: Okay. We basically initiated the approach to various schools. We just offered to do this curriculum and showed the curriculum we had. It was a great opportunity for teachers to either learn something about an area that they were going to eventually have some responsibilities, to getting a little free time from their teaching if they didn't intend to pay much attention to it. So it was a no-lose situation for most teachers--it worked. It fit very well; we got very positive response both in the willingness to have us come in and then a very positive response to the curriculum, itself. Kids loved it. It was just great.

I mean, it was the most basic stuff. It might be about somebody coming in and telling about their acting career, but they happened to have a learning disability, for example; or somebody who is an artist doing certain things and maybe has a physical disability. So the content of the art or whatever was really the content but then the questions about: "But well, how do you paint? And how do you hold that brush?" or, "and what happens at night to you? Do you have children?" You know, "How do you have children?" [laughs] Kids would ask the most outrageous and really wonderful questions, because it was a welcome environment. There were no off-limits, and people came in welcoming all those questions but didn't force any of that curriculum down anybody's throat, either. It just really emerged as part of the process of getting to know this interesting person, so it was very good.

I think that what we saw happen was other replications of that kind of project took place, then, across the country. So

there were a number of replications of the project which, you know, I think really said there was a tremendous need in the schools to begin to introduce the concept of different abilities, different ways to do things, and different kinds of kids.

We made it a very universal approach and we developed--we wrote a booklet about different disabilities and we left resource materials. We always had some reading, children's reading, that somehow talked about differences or disability. There isn't--or at least there wasn't--a heck of a lot of children's literature at the time, but we found interesting stories from which to draw discussions and so it worked.

It was a lot of fun because I worked with Judi Rogers and Corbett O'Toole, in particular, and we really got to know each other. We've been friends all these many years since. It was kind of fun. That was in the early days when we really thought the law was going to have a tremendous impact on education in the schools.

Jacobson: That was 94-142?

Brand: That's right, public law 94-142--the "education for all handicapped children" [laughs] law. That was what it was called before it was re-authorized as IDEA.

Jacobson: Now at that time CIL was on Telegraph Avenue and I remember there was the main building, but then there were satellite projects which were part of CIL but were not housed in the main building. So can you describe where the KIDS Project was located.

Brand: Well, the office where we worked when we weren't in the schools was in an office building across the street from the main office at CIL. At that time DREDF was there and there were a number of different projects, you're right. I guess you could call it in some ways a satellite project. The funding went through CIL, so in that sense we always worried about if we'd get a paycheck, like anybody else who worked at CIL. But we were pretty isolated from the mainstream of CIL which was, in many ways, in keeping with the nature of our project, being pretty much off-target from what most of the stuff that was going on at CIL was all about.

Jacobson: Did you get any kind of support or encouragement?

Brand: Yes, Judy Heumann was extremely supportive of this concept. I mean she was a very strong proponent of mainstreaming, at least

in those years, and well, today as well. So certainly there was support there, but CIL was a huge mass of projects and people were pretty well, you know, in their own little cliques working on their projects. I felt that that's certainly what the KIDS Project was all about.

Jacobson: Jackie, you mentioned that DREDF was there, also, but at that time wasn't it called DLRC [Disability Law Resource Center]?

Brand: I think so, that's right. When Bob Funk was running things, he was there at that point. And then, oh my God, what do they call this--a senior moment? [laughter] Eric--

Jacobson: Dibner.

Brand: Dibner was there. He was in the offices there, too, and I can't remember what his project was at the time--was it the ramps and the accessibility stuff for the City of Berkeley? Right? Yes, that's right. I remember, he came out to the house and helped--we talked a little bit about ramping our house. I think he was there, too.

Jacobson: And wasn't job development--

Brand: In that same place? Might have been.

Jacobson: Or was it half a block away?

Brand: I'm not sure, I don't remember. It goes back too many years. You'll have to ask Corbett these questions. She'll probably remember. Yes.

Jacobson: Jackie, did you ever have any connection with Ed Roberts or Phil Draper at that time?

Brand: Did I have a connection with Ed?

Jacobson: Yes, or was it mainly with Judy Heumann?

Brand: Well, I certainly knew and talked with Ed over that period of time. Ed's relationship was different. He operated on a different level--let's put it that way--in a sense that I don't think he was as connected. He got more interested personally in talking to me when we began to do more technology stuff. That was of interest to him. I think when I was doing stuff around education I would have to say Judy was more interested in terms of the leadership at CIL. Judy as an educator was always very interested in education, as you know. So I think

Ed was probably supportive, but I don't remember any strong connection with him there.

And it's interesting to me, actually, that I didn't get to know Zona [Roberts] in that context. It's funny, our paths have crossed, but I don't really know Zona and consider that kind of a loss. One of these days I'd like to reach out and get to know her a little bit. Certainly at that time it would have been really helpful to get a perspective from a parent who had different experiences.

Search for Appropriate Education for Judith

Jacobson: What was happening in your family when you were working with KIDS?

Brand: Well, we spent a lot of time looking for good early education programs from infant stimulation through preschool type programs to early school programs. That's what drove me to be interested when I saw how little existed, how little experience people had, how little knowledge people had, and how little willingness people had to even consider having Judith in their program.

Basically, the recommendation that was made for Judith was to be placed in what was called a development center, which was kind of an institution, essentially. It was a baby-sitting program, really, for people that were considered not able to benefit, I guess, from education.

Jacobson: Where was it?

Brand: The development center was in downtown Oakland. And we went to visit one--we went to visit it at one point, and were given a tour by a youngster who was there, who was probably at least as smart as I was, who had just been basically chalked off because the kid happened to have some disability. I don't remember what the disability was. The development center was the option that was proposed to us. It was completely unacceptable to us and so we were in this position of having to figure out what we were going to do.

Jacobson: And that was a preschool?

Brand: Actually, the development center served kids from age about three to age twenty-one.

Jacobson: Oh.

Brand: Because the content of the curriculum was pretty nonexistent, I guess [laughs] they felt they could cover the whole range. I don't think the development centers exist today. I think they're finally closed. Thank God. But a lot of kids were thrown away, basically. I mean, a lot of families were told by professionals that that was the right place for their kid, that they would be, [quote] "with other children like them, they would be happier and more comfortable, and that they would be safe and taken care of." I think that that appealed to a lot of families who were facing disability for the first time in their lives, didn't know--had no context, didn't know how to deal with it.

So it was really shameful what got called education for kids with disabilities. That was just horrible. They sought us out; they called us more than once to encourage us. I mean, they were actually looking for bodies, which is about the way they treated people, because if they didn't have enough students, they couldn't keep their doors open. So that was a problem for them.

So Jude went into a series of different programs as we searched to find the best programs for her. She went into a little private kindergarten program called Circle Preschool in Oakland. In the past they had included a couple of kids with what they would have considered minor disabilities and so they had kind of broken through a certain barrier already and were open to the notion of considering Judith. She spent a year there and it was really quite a nice program for her. That was in Oakland, in a church in the hills of Oakland.

And she went to a program, a preschool program, also, that was sponsored by--well, at that time called ACAMR--Alameda County Association for the Mentally Retarded. Do they still exist?

Jacobson: I don't know.

Brand: That was a pretty good program. It was a program, for young, disabled kids. And she got some OT [occupational therapy] and she got some speech therapy. Actually that's where she first met Amy Tan, the author of Joy Luck Club. Amy worked with Jude for a long time and became very important to Judith as an early link to developing her speech.

Then Jude went to Martin Luther King Children's Center in Berkeley where they were beginning to mainstream some kids.

They had had some experience in integrating kids with various disabilities. They already had a little boy there with autism and a little girl with spina bifida. They had a handful of kids with disabilities and a commitment to including all kids as fully as possible.

At the same time, Jude was going through intense therapy. I think I mentioned Clara Lee Edgars at the last session. As a result of going through that training, we hooked up with a young woman by the name of Kate Sefton who worked with Jude many years, actually, on an almost daily basis doing therapy, physical therapy with her--developmental therapy of the type that Dr. Clara Lee Edgars had taught. So Jude had a pretty full schedule.

She also worked for a little bit with people from the Blind Babies Foundation who came to the house. After Jude's surgery it was unclear what her vision was. It was changing: she went from being "lights-out" blind to developing some light perception to seeing shadows and movement. These changes were slow and incremental, but we spent a lot of time trying to understand what Jude could see and finding ways to stimulate her to use the vision that was returning.

You know, being a parent of a young disabled child was certainly a full-time job. I did some other things, as well. For example, I participated in a support group for parents of kids with disabilities for a brief time. That was sponsored by ACMAR, the Alameda County Association for the Mentally Retarded, as I mentioned earlier.

I did a little bit of talking to groups about parenting a young child with disabilities. I went to Children's Hospital and met with a group of physicians to talk about what it was like to be parenting a child with disabilities and how to improve communication in the medical world. I was interested then--and still--in breaking through those barriers to communication. So it was a very, very busy time.

Also, because my emotional stability was still kind of up and down, having gone through quite a long period of Jude being very medically fragile and all of that, I had my good days and my bad days, too. There were days that I wasn't much useful for anything; regardless of my emotional state on any given day, it was a very busy time for us.

Jacobson: What happened when Judith was ready for elementary school?

Brand: Well, one of the things that happened was we happened to--Steve and I happened to be on a committee in Berkeley to do a search to find a new director of special education. Our committee interviewed and the district hired somebody by the name of Nancy Kaye, who was great. She came into Berkeley and found a district that needed enormous massive change and did her damndest, really, to push the district in new directions. She worked with us very closely to try and create a good educational environment for Judith--really, did everything she could. But what she couldn't do was change current staff who weren't trained, or didn't know, or didn't have the right attitudes, to be doing the right things. So after a year of really struggling to have Judith stay in the Berkeley schools we decided to start looking around for a different school district that would have more positive--not just attitude, but some experience in serving kids with disabilities.

I think that small school districts like Berkeley were used to shipping kids away to other districts instead of developing their own capacity. Nancy Kaye said, "We're going to educate all of our kids here in the district." And that was the right thing to do, but the fact of the matter was that the schools weren't very well equipped. We would go visit Judith's class and find that an aide had her out on the yard, sunning herself like she was like a sickly kid with tuberculosis or something, while everybody else was inside reading stories. [laughs] She should have been in the thick of the academic environment, and so it was very, very frustrating.

Jacobson: When was this?

Brand: I'm terrible on these years. I'm going to have to figure--I'll do a check of all these dates and get back to you. She had to have been six or seven at that time and she was born in '74, the end of '74, so it would have been '80 or '81.

Elementary School Special Education; Middle School Mainstreaming

Jacobson: Jackie, you were talking about Judith not really being appropriately educated in the Berkeley schools. What did you do?

Brand: Well, I wanted to mention something we faced in Berkeley and in all of Judith's public school years, this tremendous dilemma that I think is faced by parents of the question of

mainstreaming versus special education. My feeling is that neither solution is a 100 percent good solution and that it's a choice that we're forced to make that's an unfair choice.

In Berkeley, for example, while we were struggling with Nancy Kaye's support and help and a lot of people's support to have Judith be mainstreamed into a typical kindergarten-first grade classroom, we were painfully aware of how isolated she was from other kids with disabilities and how hard that was on her psyche and on her social life, as well. And so, to help counteract some of the isolation, with Nancy and Judi Rogers, we created a little women's group that met at our house for several sessions. It was made up of young girls with disabilities that would get together periodically. Nancy Kaye and Judi Rogers also had disabilities, and so it was a nice opportunity for peer mentoring. It was an effort in the direction of trying to connect Jude with other young girls with disabilities.

But that unfair choice between special and common education was a theme, I think, throughout the years that Judith was in public school. We went back and forth over the years, actually, depending on Judith's greatest needs at any given time.

When we left Berkeley, very discouraged and cynical about the value of mainstreaming, we moved to El Cerrito and she went into the Richmond public schools where she actually went into a special ed classroom at Castro School. We turned in mainstreaming and typical education for a really strong teaching curriculum and more content and also more connection with classmates. There was some reverse mainstreaming that took place, and the kids were mainstreamed into other classrooms for parts of the day, but in fact, I think that wasn't terribly successful. Judith spent the next few years in largely special ed programs at Castro School.

When she hit middle school, once again we were concerned about what that was going to mean for her and we worked with some people who were establishing a new middle school program in the public schools in Richmond called Adams School. She became one of the students piloting a program which was a fully mainstreamed program. And actually, it worked pretty well. One big problem was that the school wasn't accessible--if it had been, that would have helped a lot. [laughs] We struggled during her middle school years to get an elevator in the school and the month before she left that school they actually did get the elevator in, so hopefully it's working for other kids.

Jacobson: Did the KIDS Project ever go into any of the schools Judith went to?

Brand: No.

Jacobson: Why was that?

Brand: Because when we were doing the KIDS Project, at least initially, it was prior to Judith to being in school. Once Judith was in school, there was by then some replication of that work in the Richmond schools. What we found and one of the reasons why we moved to the Richmond School District, despite its generally poor reputation, was that it had a history of many years of educating its students with disabilities in their schools, unlike the Berkeley schools. I actually found that to be the best school district I ever worked with--the Richmond schools. From the administrators, who were totally committed to educating all students, to much of the staff, there was just a willingness to serve kids with disabilities. That was, in general, the best education she ever had.

I don't know for a fact if the KIDS-type program ever went into Judith's classroom because when she moved into the Richmond schools she really went into a segregated environment. Castro School considered itself on the cutting edge in many ways because it was a school which had special ed classrooms at the school as opposed to a special school of kids with disabilities which was more the case in most other places. So they were on the cutting edge in the sense that all the kids in the school were used to seeing kids in wheelchairs and so on. In fact, it was in the Richmond schools that I got the call--I think I mentioned to you that Judith had fallen out of the swing. [laughter] It only could have happened in the Richmond schools; she never would have been in a swing in the Berkeley schools. Not in those days--they wouldn't have allowed it. So, yes, it was interesting.

I was working on the KIDS Project earlier than she was benefiting, although in my mind I was trying to build a climate and work on developing curriculum that was going to have impact for her and for all kids, theoretically. I don't know that she really ever benefited from that, but what I've learned is that it's a very slow process and it hasn't gone smoothly and easily in this country.

Jacobson: How long did you work on the KIDS Project?

Brand: I think about two years. There was so much to do, you know, as a parent; there was just so much to be concerned about and to be involved with. For example, when Judith first went to Martin Luther King preschool, the agreement was that she could come if I was there every day. And so I went every day. I finally woke up one day and said, "This is absurd, this has got to stop. I can keep her home and be with her, what was the point here?" [laughter] But it was extremely time-consuming in trying to trouble-shoot and provide support to teachers who were terrified. It was pretty consuming.

Family Equity among Children; Siblings

Jacobson: What about Michelle?

Brand: Well, what about Michelle. [laughter] Where is she in all of this? Yes, yes. Well, my perspective, and you'd really have to ask Michelle this question, and in fact, it would be a great--I'll ask Michelle this question. Our feeling was that as long as Michelle got all the attention she needed, too, that this would all work out all right. In other words, I tried to look at this not as taking time away from Michelle, but simply spending more time parenting than an average parent would because Judith required more time, therefore so did Michelle as a function of equity in the household and giving attention and so on. And so that was a pretty consuming number of years with both the kids.

I thought Michelle was a fairly difficult kid to raise. She was quite bright and quite independent but also moody and there were issues around Judith. Until Judith had a surgery where she was medically stable, there was a lot of, I think, resentment that was growing about this baby who would cry and cry and cry and who you couldn't fight with like another sibling. Once Jude was a little older and safe, rather than medically fragile, then they fought and they could duke it out. You know, I don't mean that they really beat up on each other, particularly, [laughter] but I felt there was equity in their relationship. Michelle felt like she could have the normal sibling issues, and likewise with Judith.

They were both close and yet there were also times when they had little to do with one another. Michelle grew up a little bit on the over-protective side with Jude. She would have fights with a lot of people around things that they would say. [pause] She would get very defensive about Judith and

found it very tough with her friends and went through periods where she found it very difficult to do stuff as a family because people would stare at us wherever we went. We were never anonymous--we actually named it the skunk syndrome at a certain point. She just longed to be able to do something and not be noticed [laughs] instead of having everybody staring at you no matter what you were doing. But I think she did pretty well. I think she resented the times when Jude was in the hospital in terms of losing our attention, but basically she did fine. As she grew up I think she had her own separate interests--which was important to me, that she didn't feel that her life was somehow to be devoted to her sister. She had her own life. They each had their own lives and their own interests and so on.

Today they're very, very close. They'll always, I think, be very close. Certainly there were some tough times for Michelle. I wouldn't say that there weren't. And I do think she's a better human being as a result of growing up with a sister with a disability. I wouldn't have wished that learning on her; and I think she paid some price for it, too, but she certainly grew up with a different sensitivity toward people and not as shallow a look at people as most other people have.

You know, I think Judith taught her a lot of stuff, too. She grew up thinking that certain things that were normal, of course, because they were the way our family was and was always shocked by things that happened that pointed out, oh, that isn't the way things are.

Jacobson: Like what?

Brand: Well, I don't remember if I told you this last time but she thought everybody had therapy in order to learn to walk. [laughter] So she just had no idea, she just figured, "Well, who was my therapist when I was learning to walk?" And certain things just seemed totally natural to her because they're natural in our lives. That was always surprising.

Our circle of friends was pretty diverse so Michelle and Judith grew up, unlike me, knowing people with different backgrounds and disabilities. There was always a period with Michelle of her friends having to pass a test for her, and it was very obvious. I mean, it wasn't exactly stated that way, but it was very clear that if anyone looked cross-eyed at her sister, they were just out of there. And she did get into a couple fights at school around kids calling other kids names. Did I tell you that story?

Jacobson: No.

Brand: Okay, well, it was in about the second grade or maybe the third grade and a popular expression then--probably now, too--is for kids to call each other "retard." And that used to really upset Michelle. One day in school somebody called someone a retard in class and she came home very proud. She said, "Mom, Johnny called Susan a retard." So Michelle said to the kid, "What's wrong with being a retard?" And the kid didn't answer and Michelle said to the kid, "I asked you, what's wrong with being a retard?" And the kid said, "I'm thinking, I'm thinking." And I thought that was pretty amazing. She was very, very little. Because he had taken a category--Michelle knew plenty of kids who had mental retardation and she was saying, "So? Why is that an accusation if that's true?" [laughter] Anyway, she did get into fights and stuff and was pretty sensitive, but I don't think that's unusual. It's probably very, very typical. I'm going to ask her to say honestly now, because now she's an adult, it would be interesting to know more.

I know a little bit about the hospital times. Those were very tough for Michelle--when Jude was in the hospital and we all were just emotionally very unavailable to her even though we always had my parents come and she had lots and lot of attention. The toughest time, actually, was we decided at one point she was old enough and we took her and we went to a Ronald McDonald house while Jude was having a surgery so she could just be there. I think in some ways that was the hardest time for her. It was easier if she weren't right there. You know, we were trying to make judgments and thought maybe it would be easier for her to know what was happening than just to wonder and make it up or to feel excluded. But basically she found that really tough to be there, from her own childish self-interest really. I mean, she didn't feel like she got enough attention--people were all thinking about Judith there--there we were at the hospital, so it turned out not to be the best decision.

Jacobson: I think that's a good place to stop.

Brand: Yes, I think so.

IV SOCIAL AND TECHNOLOGICAL SOLUTIONS FOR INDEPENDENT LIVING

[Interview 3: November 22, 1998] ##

Project PLAE--Integrated Recreation

Jacobson: Jackie, we talked about you working at the KIDS Project and then I know you became involved in the Project PLAE. Could you tell me about that?

Brand: About Project PLAE?

Jacobson: Yes.

Brand: Yes, there were some people trying to get a project going which would be an integrated project--a recreational program that would include kids with and without disabilities. There were a number of us who were really interested in looking at the way in which kids with disabilities could be part of a more general social and recreational program instead of being put in special classes or grouping for just kids with disabilities. So I was part of a small group of parents who met with the people who were creating Project PLAE--Susan Goltsman and Daniel Iacofano. There was Barbara Lubin and myself, Judi Rogers, and Marilla Arguelles, who were all parents. We met in the planning stages and then our kids were involved in the launching of Project PLAE.

Jacobson: And they were all parents?

Brand: The people who put it together--Susan and Daniel, Susan Goltsman and Daniel Iacofano--were not parents, but they came to parents to get feedback about what they wanted to see for their kids and the parents were pretty involved in it.

Jacobson: Susan and Steve--who were they?

Brand: Ask me that again?

Jacobson: Who were Susan and Steve?

Brand: Susan and Daniel. They had an architectural firm and they had a tremendous interest in creating environments that were intrinsically accessible to everybody.

Jacobson: Okay.

Brand: Yes, and they had contacted me, I think through Barbara Lubin. Barbara knew them somehow or another. And we began to work together. They really were some of the earliest people I knew grappling with the concept of universal design, who probably had been way many years before I had any inkling of what that might mean. They were looking at it really from an architectural and design vantage point, that if you design environments intrinsically to work for everybody then it works for everybody, and that's what they were interested in doing.

They created summer programs in Berkeley and worked very hard to get a good mix of kids of all different ages and different abilities, both. And it was a wonderfully successful experience.

I really consider myself more to be a beneficiary of the project than really a creator of the project. We all worked hard to give good feedback and to make sure it worked and supported it and promoted it in a lot of places. I was on their staff a little while doing a little bit of work, but basically speaking, they really brought together a team of teachers and artists and theater people who pulled together the program. Both of my kids were involved for years and loved it.

Jacobson: Now what does Project PLAE stand for?

Brand: Yes, PLAE is P-L-A-E and that stood for Playing and Learning in Adaptable Environments. It was really a terrific program. I don't know if it still exists today, to tell you the truth. Does it, do you know?

Jacobson: I don't know. Was it based in Berkeley?

Brand: Yes, it was based in Berkeley. It was all on the yard--is it Washington School there, at Milvia? There was a whole yard that we could take over with gardens and so on in the summer. And there were circus courses, there were gardening courses, and there were radio stations--it was very pre-technology time.

Judith loved it and I think all the kids enjoyed it. It was a really nice summer program. And it was a very welcome change from the typical Easter Seals summer therapeutic programs that seemed to be the main offering for kids with disabilities. [laughter]

Accessing Assistive Technology to Enhance Judith's Development

Jacobson: Yes, we know about those. So was it at that point, or after that point, you became involved in technology? How did that happen?

Brand: Well, it began to dawn on Steve and me, as Judith started school and was in her early years, that the tools that were offered at school for the kids to use to learn with were not tools that were going to be useful for Judith.

Jacobson: For example--

Brand: For example, books: she couldn't read the books. For example, the blackboard: she couldn't see the print on the blackboard. For example, pencils and paper: she didn't have the fine motor capacity to write, and so though she had a great interest in the academics of school, the tools weren't right for her. The tools didn't work for her, and we didn't know exactly what would work for her, but here was this, you know, new microcomputer revolution before us with promises that it was going to just revolutionize learning and teaching and the way in which we function in society. And our first thought was, well, why shouldn't these revolutionary new tools work for Judith in place of some of the tools that were in school that weren't working for her.

Jacobson: Now, what year--

Brand: I knew you were going to ask that! [laughter] Let me think-- it was the early eighties, 1982. Is that close enough?

Jacobson: Okay.

Brand: In fact, Steve, my husband, really got the computer bug way before I did. He took a year's sabbatical leave from teaching school and went back to school and learned some basic programming and just tried to learn a little bit about microcomputer technology so that he could try and help fashion some kind of system to test out with Jude.

We were getting into this with her just a little bit before the tools really were there. It's still true that tools aren't quite there for her. For example, she needed some kind of a programmable flat surface with large blocks of a keyboard that she could easily touch with a fist to operate a computer--and though the keyboard had recently been developed, the interface to make it work with the computer hadn't yet been developed. We first tried this keyboard, or bought this keyboard from a company in Oakland called Unicorn Engineering; it since has changed its name to IntelTools.

Jacobson: And that was started by Steve Gensler?

Brand: Steve Gensler, that's exactly right. And Steve brought that keyboard to our house one night and said, "Be sure and call me if you ever get it working. I'd love to see how it works." So he had designed the keyboard, but hadn't really seen the whole thing working this way. I believe he had originally designed that keyboard for Frank Moore who was a friend of his and a man with a disability. I don't know if Frank ever used it or not, but--

Jacobson: You know, I am very computer illiterate. I can use my word processor and get on AOL and the web but I don't know or understand how or why, and so I wonder if you could talk about why that keyboard couldn't work with the computer. In my mind I'm thinking, well, the keyboard had a plug and the computer had a socket, so why couldn't it just--

Brand: It just plug in? Yes, yes, well, today, of course, we can do that. We can do that with the IntelKeys keyboard and with other keyboards. At this point you could go to Circuit City or CompUSA and get an extended keyboard or various different keyboards and plug it into your computer. At that time--I don't really know the technical reason why the computer didn't have a capacity to just receive that plug-in, but there was a need to develop an interface device--I mean, a peripheral, that would communicate between the computer and the keyboard.

The device that was finally developed--there were a couple that were developed, but the main one that took hold was one developed in Washington, called the Adaptive Firmware Card--AFC. It was a pretty complicated interface card and it was the bane of a lot of peoples' existences trying to make it all work together. But it would do things--the value of that interface card was that it could turn your access, your input into the computer into a lot of different formats depending on your need. So for example, it would create a scanning array where all of the options of the keyboard would flash on the screen

and you could hit a switch to say, "That's the letter I want," or, "That's the line I want and then that's the letter I want," if you only had the ability to hit a switch, rather the standard keyboard.

We could program the Unicorn Board that Judith had so that we could try out different things with her. When we began we didn't really know how much Judith knew because she wasn't able really to communicate it that well, so we could do some very basic cause and effect programming on the keyboard. We could do things like paint half of the keyboard red and half yellow and ask her to touch the red side and the yellow side; then we could say, "Okay, that was easy for her to do," and we could then program the keyboard into four parts, now, and do four different colors or four different pictures--a cat, a dog, a pig, a cow--she was a pretty young kid--and ask her to find the cow and ask her to find the dog. She could touch a dog and then she would get a barking sound back from the keyboard to let her know what she had touched. We experimented a lot with this keyboard to figure out what she could see as well as how she could use her hands.

The thing is that keyboard was exactly what she needed, because she could do, first, two options and then four and then eight options, and we could keep developing it and changing it as she demonstrated what she could do. Unless we did, she'd get bored. There was only so many times you could ask her to touch red and then to touch yellow. It gets old pretty quickly. You know how to do it: you do it ten times, you do it twenty times, and then you're not interested anymore.

So we got to the point where we actually had sentences on blocks of the keyboard where she could then compose a letter or put together lots of thoughts. Eventually the keys got smaller and smaller, there were more and more divisions on that board, until she had essentially a full keyboard to work with.

Had we shown her that full keyboard right at the beginning, there was no way she could have done it. She needed to build her ability to distinguish and to move between smaller and smaller distances. That was the developmental thing that she needed, and this keyboard uniquely provided that opportunity. It's like showing a very young child a standard keyboard and they go banging on it because they don't have the fine motor skills yet, and then they get bored and that's it. Instead, the computer became a real learning tool for her as it could develop and evolve on the keyboard as she developed and evolved both in a physical sense and gain the fine motor skills--and

also in a cognitive sense as she went through the developmental stages.

This keyboard and interface card did a lot of things for a lot of kids and adults who otherwise were really blocked from accessing a computer, so this was the beginning of my understanding about the power of assistive technology. And we also realized that this was not easy stuff to do. It would have to be a lot easier to use before many people would benefit from it.

Creation of the Disabled Children's Computer Group, 1982

Brand: There were definitely people who knew a lot more than we did at the time--but we knew a lot more than most people because we were starting to learn about it. So there was this desire to create a center, a place where we could get together and share information, that led us to create what was first called the Disabled Children's Computer Group.

In 1982-83 we began to have meetings, periodic meetings, up at the Lawrence Hall of Science in Berkeley. They donated space to us and worked very hard with us to help launch an organization.

When we had our organizational meeting at the Hall, we were amazed by the number of people that came to the first meeting. It was just incredible. And it was incredible on two levels: one was just the sheer number of people who were interested in this field and wanted to learn more, and the other thing that was so interesting to us was the diversity of people in the room. There were educators, there were adults with disabilities, there were kids with disabilities, there were parents, there were teachers, there were doctors, there were engineers--just a very broad range of people that I had never seen in the same room together--very interested in this issue. There were a lot of tech-ey types who were really fascinated by the potential of applying their skills and knowledge to serve the needs of people with disabilities.

Jacobson: How did you get the word out?

Brand: How did we contact those different people?

Jacobson: Yes.

Brand: Well, the Hall helped a lot--Lawrence Hall of Science. We just started calling everybody we knew. We had been talking with people at the Lawrence Hall of Science and we had met with a number of people. In the early days, Gregg Vanderheiden had been involved with some early meetings with us. Alexandra Enders had been involved. Debby Gilden from Smith-Kettlewell, Linda DeLuchi and Larry Malone, specifically, from Lawrence Hall of Science had been involved. Hod Gray was a parent that was involved. And there were a number of parents. I don't remember everybody right now, but somehow or another word traveled pretty fast. Really, as you know, when you have a child in school in special education with a variety of needs, you tend to also, all of a sudden, have a very large circle of people who are interested.

And in fact, that first meeting at the Hall was in the auditorium and people stood up one by one and introduced themselves and it was funny--people laughed--because people stood up one after another and said, "Well, I'm--well, at the time it was Shoshana, but--I'm Shoshana's teacher, and I'm here to learn about technology." "I'm Shoshana's speech therapist, and I'm here to learn about, you know, what could be done." And, "I'm Shoshana's physical therapist," and, "I'm this--" and so she had this huge set of resources of people. And there were a lot of educators from a lot of different fields who filled that room that day.

Jacobson: How many people would you estimate were at the first meeting?

Brand: Oh, I'd say about fifty.

Now, the other thing I'd done is I'd gone as a guest to speak with a parent group at UCP two weeks before that, and invited that group to come. There were a number of people from that parent group that came, as well. We decided at that first meeting--we asked people who were interested in creating an organization to stay after and we'd form an advisory committee. We also took a collection. We probably brought in about ten bucks or maybe \$11.22, or something to cover the cost of the paper cups and coffee that we had bought for the evening. There were quite a good number of people who stayed after and constituted themselves as kind of an advisory committee. That led eventually into being the first board of the organization as it was established.

What we did was, for a good year or year and a half, we met about once a month at the Hall and we'd try and do demonstrations. Anybody who was doing anything with technology was invited to come and show us what they were doing, and what

the strengths were and what the dilemmas were, and just begin to introduce us. So it was very exhilarating because very early on you could see that this technology was going to totally shatter preconceptions about what people could and couldn't do.

Jacobson: Jackie, you mention Gregg Vanderheiden and Alexandra Enders and I know they've both been very important in computer technology. What were they doing at that time?

Brand: Well, Gregg was already at Trace, the Trace Research Center.

Jacobson: Trace?

Brand: Trace is a program at University of Wisconsin at Madison. It's a research and development center focussed on accessible technology, assistive technology, today promoting universal design. Gregg had done some of the very early work in looking at adaptations, and he's been for many, many years really the solid mainstay in this field of development and design, and continues to be.

Alexandra, I don't remember if she was working with Gregg at that time, but Alexandra Enders was originally an OT. She originally worked at CIL--Center for Independent Living at Berkeley--and has had tremendous interest not just in high-tech solutions, but in really understanding the grassroots solutions that people come up with, and sharing that information. She, even in those early days, was such a font of knowledge and experience about how people were solving all sorts of issues--to address issues that disabilities brought with some kinds of low or high technology. The idea of a community-based grassroots organization just intrinsically was the kind of thing that Alexandra would obviously support. Since then she's gone to the University of Montana in Missoula. She's currently the president of RESNA. I don't know what RESNA stands for anymore. Originally it stood for Rehab Engineering Society of Northern America, but it's changed its name. But it's kind of the trade organization of engineers who are interested in accessibility and assistive technology. So she's been just a key individual in the field.

So they were in on some of the very earliest discussions when we first were trying to get things going. We reached out everywhere where we could find anything going on. One of the things that we saw early on was that there were little efforts taking place all over the world, probably--but to our knowledge, all over the continent--where somebody with a

disability had a need and they or a family member or a friend were trying to address the need and create a solution.

Those solutions were kind of mom-and-pop type solutions and they never became part of the mainstream, so other people didn't have access to those solutions. The field was only going to grow and be effective if we could connect people who were working together in the field. That was our goal: to have people not feel isolated just trying to resolve the same problem in various parts of the country, but instead to learn how to share solutions together and have the resources to build on each other's successes rather than having to always recreate those same successes.

Some of the earliest assistive technology companies developed out of human need--one single need that was addressed, a solution that was developed, and the desire of the developers and the designers to make those solutions available to other people--trying to make a go of creating a business and so on. Most of those companies didn't last, and so a great solution would be around but they didn't have the resources to market those solutions, to produce those solutions in enough quantity to bring prices down, and so they were very expensive solutions that very, very few could afford. Eventually most of these companies just went out of business. They couldn't make a business go of it.

Jacobson: I'm going to turn the tape over.

Brand: Okay. Oh, good.

DCCG Funding and Network Development

Jacobson: How did DCCG get funding?

Brand: Well, in the earliest times we weren't funded, we just volunteered. It was a huge volunteer effort. Then we began to try--eventually, as happens if the organization is going to survive, you begin to look for funding resources. We were pretty naive because we believed so firmly in what we were doing that we just expected it to be so easy to raise funds. I laugh when I think back on it. Like, I remember we wrote a federal grant and we had help from Linda and Larry at the Hall. They actually helped us with the grant writing. And I remember being so bitterly disappointed when the first federal grant we

wrote didn't get funded. I didn't understand it. It looked like we would have been perfect. But eventually we began to get support from community foundations, private foundations-- East Bay Community Foundation, the Stulsaft Foundation--a number of foundations began to fund our work, but we were always a fairly small operation in terms of the dollars. It was not that easy to get support, although I guess I should say in the earliest years it was easier than it became later on. In the earliest years, because it was a new, brand new and exciting project, there was a lot of interest.

We also worked with many of the developers very early on because in addition to needing dollars to try and have staff around, we needed stuff--we needed the new technology as it was getting developed. We needed to communicate with the designers who were designing the next generation of products to talk about what worked--about how, for example, the Unicorn Board was great but what its flaws were and what we wish it could still do, and the same with other devices. We needed access to companies, the main companies like Apple Computer and IBM Computer, who were designing the products that were either going to be more useful to us or less, depending on how the next generation went. So over time we began to build our contacts with the developer community and the technology industry, and eventually made contact with Apple computer.

That was one of our more successful contacts. I remember trying to contact Apple as a parent with a kid with a need and having a heck of a hard time getting their interest. But once we had a functioning organization and center, there was a very great interest that came from Apple in the work we were doing. Shall I go into that?

Jacobson: Yes.

Brand: We had made some effort to contact Apple, but had not been successful in our first tries. But there was a conference that year--it had met for its first time the year before, and had its second conference in Minneapolis--a meeting called Closing the Gap--CTG. It was an assistive technology conference. Our new organization took a collection, basically out of our own wallets, to send me and one other parent to Closing the Gap in Minnesota to learn what was happening around the country. This was one of the early activities of the Disabled Children's Computer Group.

When I got there I found out that the keynote speaker for the conference was somebody who had been hired to set up an office of special education and rehabilitation at Apple, and

his name was Alan Brightman. I heard him speak and I was so impressed with what he had to say, I decided he would love to know about us. So I patiently waited outside the room where he had spoken and practically had to trip him to slow him down, but I did and I said, "Got to talk with you!" And we sat down and I told him about DCCG.

He was pretty excited. He was just trying to put together his initiative--what was he going to do with this new office that he was hired to create. I asked him, "Would you consider coming up to DCCG in Berkeley--it's only about sixty miles away from Cupertino where Apple is--and talking with us and let us know what your plans are?" And he said to me, "I have a better idea. Would you think about coming down to my shop and telling us what you're doing?" I said, "You're right, that's a much better idea." So we gathered a group of us. About fifteen of us actually went down to Apple Computer, not so long after that Closing the Gap conference, and did a three hour demonstration and discussion with a huge room filled with Apple employees.

Jacobson: Let me go back a minute to the Closing the Gap conference. Who put that on?

Brand: It was two parents--Bud and Dolores Hagen were their names. They had a son with a hearing impairment, a severe hearing impairment, and they were just interested in what this technology was all about, and so they put this meeting together.

Jacobson: And was it a nationwide conference?

Brand: It was intended to be and it increasingly became a nationwide conference, yes. It attracted mostly educators, even more than consumers. It became a pretty strong education-focussed conference and it attracted a huge number of developers of new products, so it became the best place in the country, in the world, to look at new technology as it was being developed--assistive technology. For a number of years it was the only place, really, where you could see a huge exhibit hall filled with new products.

Jacobson: How did you find out about it?

Brand: They had a little newsletter and as I started searching, you know, calling everyone and asking, I just learned about them. In the early years, Dolores Hagen wrote a book about computer technology for people with disabilities and it really was very inspiring to me, it really got me started. I called Dolores right away and had a great talk with her.

When I went to CTG, it was a very wonderful experience. I walked in on her pre-conference workshop that she was giving and she saw me and I saw her, and she just came over--she stopped what she was doing and came over and gave me a big hug. She must have seen I was a totally lost parent trying to figure out what this world is all about. It must have been all over my face, because it was just an immediate connection.

Jacobson: That's great!

Brand: It was really something. She was just a real pal. She introduced me to the whole world of assistive technology. She took me around and just introduced me to the people in the country who were there at her meeting. I didn't know a thing.

And at that conference, too, there was another thing. I met another parent from Minnesota. I don't remember how we connected but she said, "I know you have no money. It's obvious to me you're watching your nickels." She said, "Check out of that hotel. You're going to come stay with me," and I did. I moved into this woman's house and she gave me lessons on how to use a computer. I didn't really know much at all. She taught me about copying disks on an old Apple II, and we stayed up late into the night.

Jacobson: You got this computer group together and you knew nothing!
[laughs]

Brand: I knew nothing. I knew it was going to be very important in my kid's life and I knew I had to figure it out. I had a very odd kind of knowledge. I was learning about assistive technology, but I didn't really know about general technology. I eventually, almost embarrassingly, took a class in "What's a computer," I remember, up at the Lawrence Hall of Science. It was an extension course.

I remember how I knew all this kinky stuff, like I knew about adaptive firmware cards and special keyboards and board synthesizers, but I didn't really understand RAM and bytes and the most basic stuff people would learn, and so I needed to sort of get a basic understanding.

What I found was that because nobody knew about assistive technology, about ten minutes after I started learning, people wanted me to be the expert, because nobody knew anything and people were desperate to find somebody who knew something more. That's how I was feeling--desperate to locate people who knew more. It wasn't from a technological interest, really, that I fell into this field, it was out of having a vision of what the

technology might mean--not how it worked, not really what made it tick. It was just knowing that a machine can follow instructions to do things that somebody else wouldn't have to do to accomplish great things--to be able to write, to be able to communicate, to be able to just get down your ideas on paper. That's what drove me.

So I spent the week at this parent's house, and at this conference at CTG, and my world was just blown away. I came back filled with the realization that we were on to something so powerfully exciting, so dramatic, with so much potential--not just for my kid, but for a lot of people. So that kind of reinforced for me that we needed to build an organization and we needed to form partnerships with other groups like the Apple Computers in the world.

The Apple Computer Connection, 1986

Jacobson: So you took a group, then, to Apple?

Brand: Yes, kids and adults and people who were using the technology, people who were teaching about the technology, and we did a three-hour show and we kind of blew their socks off. [laughter] It was after that point that Alan Brightman brought me in and said, "Is this thing you're doing a Berkeley aberration? I know Berkeley does a lot of weird things. Or is this something bigger than that? Is it something that has real potential? Is this the kind of program that could be replicated in other parts of the country? And would you want to find out? Would you want to work with me on trying to promote this idea, find other groups like yourself, and come together in some coordinated national way to have some big impact?" Over time, that led to my going to work--first I tried to work at DCCG and Apple in a combined way, but eventually I left DCCG to focus my energies on the work at Apple. My whole job at Apple was simply to help to facilitate the growth of other similar organizations like DCCG.

I spent several months on the road, returning phone calls--one of the things that had happened while I was at DCCG was that people called almost immediately from all over the country, saying, "We want to do something like this, we're trying to get something going, can you help us?" And I had to say, "There's nothing I can say except go do it--that's what we're trying to do. This is very exciting, I wish you the best." I really had no resources to help them out in any way.

But when I went to Apple, I could go back to my phone messages and call back all these people who had called me over the earliest months and say, "You know what? I think I can help. Are you still really interested in pulling something together? Can you organize a meeting? Let's talk." I began to travel around the country and meet with all these different groups and people who had called me, and found some incredible little pockets of amazing people doing amazing stuff.

I also began to meet and get to know a lot more of the developers who had found their way to Apple. Apple was just such a source for finding the people in the field who were interested. They got a lot of calls, and I got a lot of calls at DCCG, and out of that research and traveling and meeting with people, we created an organization called--well, at the beginning it was called the National Special Education Alliance--NSEA. I was never good on names. And with Apple we launched a national organization of eleven centers around the country committed to applying microcomputer technology to the needs of people with disabilities.

Jacobson: Now this was around 1986?

Brand: Yes, '86-'87. That's good.

Jacobson: The reason I remember is that Mary Lester called me at the time because there was a job opening at DCCG and she had asked me if I'd be interested in one of the projects. We had just adopted David and I couldn't figure out how I would manage to be a working mother. But I recall that she told me you had just gone to work for Apple.

Brand: Yes, so it was '86 that we were doing the traveling and it was April of '87 that we launched this thing. And when did you adopt David?

Jacobson: He came out March 20 of '87.

Brand: So it was exactly the same time.

Jacobson: Yes.

Brand: Exactly the same time.

Jacobson: How's that for a memory. I can't remember what happened two hours ago, but [laughter] I remember that.

Brand: Yes, that you'll remember.

Well, so we brought together eleven different groups and we went to a national meeting of the Council for Exceptional Children in Chicago and, based largely on our hopes and expectations, we had the gall to announce ourselves a national organization. We met for three days or so with all these different centers, and shared what we were all doing. Then, with Apple's support, we hosted a big, fancy dinner party for all the vendors who had come to Council for Exceptional Children who were interested in assistive technology and kind of brought them in as partners. We didn't know what the heck we were going to do with them, but we knew that we needed to involve them in some way. And Apple was really the hook. They were interested in having business with Apple and were very excited about this whole process, so that was the beginning of this national organization.

We immediately put everybody on email, and this was in the early days for email. Apple Computer had its own proprietary system called Applelink, and everybody was on Applelink and everybody communicated with each other virtually every day. It was unbelievable. We would get emails like, "A family just came in and the kid is trying to do math and he's really interested in race cars, and he's not able to really handle the computer, and help! What ideas do you have?" And within twenty-four hours from all over the country, people would throw out everything they knew, everything they had come across from, gosh, "There's somebody in a small town in Kansas who's just developed this great little car-racing program that has math built into it," to, you know, "I just met with somebody and here's a way I used a new keyboard--it was very successful."

We basically gathered information that was otherwise unavailable. It wasn't documented anywhere. It was direct experience and feedback and sharing of resources that all of a sudden gave us a sense that there was now a national focus on issues we had been struggling with, one by one, in our own little programs, in our own homes, in our own little centers. And so it was a very empowering process, and a very exciting one, the early creation of the Alliance.

Eventually the National Special Education Alliance became the Alliance for Technology Access. We realized it was not our interest to remain part of special education, just working with kids and not including anybody who had a need. Early on, because so many of us were parents, we were focused on children, but the truth of the matter is, when we set up a center in a community, there was no place else that anybody was doing any assistive technology, so adults wanted access to those services, not just kids. And how could we turn away

anybody? We had no desire or wish to do that, so we quickly realized that we needed to move and have a focus that was broader.

Jacobson: Now, I think I read somewhere in your resume that there was a connection between the Office of Special Ed and Apple.

Brand: Meaning the Federal Office of Special Ed?

Jacobson: Yes.

Brand: No, they just called themselves the Office of Special Education and Rehabilitation at Apple. That was its department name.

Jacobson: Oh, thank you for clarifying that.

Brand: Yes.

Jacobson: I know it surprised me when I read that title.

Brand: Yes. We did do a trip to the White House at one point, and we did talk with Madeline Will--George Will's wife--Madeline Will, who was--gosh, she must have been Secretary of Education at that time, or Assistant Secretary of Education. And you know George Will, the columnist, he's a very renowned political commentator. They have a son with Downs' Syndrome. So we went to Washington and brought a video of technology and introduced Madeline to the concept of technology.

At another point the White House contacted us at Apple, and we talked about doing a huge event at the White House around assistive technology, and they asked us to come out and meet with them. We did go out, but I don't remember which office we met with at that point. There were some connections with Washington early on, but not enduring connections. They were just [laughs] something more than photo-ops, but something less than substance.

We had a chance to do some interesting things with the organization while we were at Apple because resources were so available to us. One of the things I was able to do was pull together a think tank of people. We brought this group of people together quarterly for about three days and we talked into the night--you know, through three days--about the future of technology and the potential of it all, and did planning and thinking.

Also being at Apple I had the opportunity to really be closely involved in hearing about the next generation and

giving input into the next generation of technology. I think that for those of us who had those opportunities--and many others way more than myself: Gregg Vanderheiden was somebody who they brought in very frequently, and there were others, as well--we had a chance to really impact on the development of the Macintosh, in particular, and the way in which it could incorporate a lot of accessible features.

I became very, very interested in the way in which we could promote accessibility into each succeeding generation of the technology and start to move away from the constant retrofitting or fixing the technology as it comes out. If it doesn't work, we're constantly trying to look for the next adaptive firmware card to make it work. How much easier to build screen enlargement into the Macintosh and the ability to use a single finger in sequential mode, instead of needing to use several fingers at once. The features that got built into the Macintosh--I really learned a lot about the early thinking about universal design, there.

Being at Apple also allowed us to do tremendous training for centers across the country. We took everyone to Harvard for a couple of weeks early on, and the School of Education there engaged all of our centers in intense training and learning about technology and curricular modifications and so on. We worked with an organization called CAST--Center for Applied Special Technology--who were on the faculty at Harvard.

We brought people from all over the country together for a huge meeting in San Jose where we did trainings. We did multiple trainings thanks to the largesse of Apple. Then Apple funded the equipment and startup for all these different organizations. We got a lot of technology distributed, both Apple technology and assistive technology, to all these different centers. It was pretty phenomenal for the early years when Apple was involved. It really was extremely helpful. We grew to have about forty centers around the country.

Builder of Organizations--Alliance for Technology Access and Other Related Spin-offs, 1987-1996 ##

Jacobson: So Apple funded centers?

Brand: Yes, initially they funded, not the day-to-day operations of the centers, but they provided a lot of resources. Philosophically, the idea was any center that was going to survive had to survive because it was supported by its local community. An external force providing that funding, although it's always wonderful to have, isn't really going to create a community institution and be formed and shaped by the community. Plus, as wonderful as the support was from Apple, in the end we knew that our missions were different and that Apple support wouldn't continue indefinitely.

Our missions were distinct: the bottom line for Apple was to make money, the bottom line for the Alliance for Technology Access was to provide technology and information about technology to people with disabilities. I always worried about the day when it would become not so interesting to Apple anymore, and we were always trying to prepare for that eventuality. In fact, even in the earliest days of support by Apple, I had Apple lawyers preparing our nonprofit status for the organization. I just realized that if we put that nonprofit organization on the shelf at Apple until we needed it, when it came time for us to separate from Apple, we would be ready to do that.

Jacobson: And that nonprofit organization became the Universal Service Alliance?

Brand: No, that nonprofit organization became the Alliance for Technology Access.

Jacobson: Okay.

Brand: Well, originally it became the National Special Education Alliance and then that name was changed to Alliance for Technology Access.

Jacobson: Okay.

Brand: Yes, yes, so in other words, even while Apple was training and working and providing equipment, we had their lawyers helping us to prepare to be independent of Apple.

Jacobson: I see. And so you were there from 1987 to 1996?

Brand: From 1987 to--at the Alliance you mean?

Jacobson: Yes.

Brand: Yes, until 1996, that's right.

Jacobson: But in 1995, you started another organization. [laughter]

Brand: Bizarre.

Jacobson: You've had quite a career of--[laughs]

Brand: Well, starting Universal Service Alliance was really done originally in my capacity at the Alliance. It's really a project of the Alliance for Technology Access. It was designed to look at and advance universal service, but not as a stand-alone organization. It's a coalition of many organizations, organized under the umbrella of the Alliance for Technology Access.

So yes, I have created several different organizations and later on we'll talk about ILN [Independent Living Network], too--[laughs] yet another. But one is kind of built on the other, like the Disabled Children's Computer Group was the first organization and from that it became one of many organizations under the umbrella of the Alliance for Technology Access. There was a desire to create a local impact organization, but to have an affiliation that could give it national meaning and national scope. So it had the benefits of a local grassroots organization, combined with the benefits of people coming together in a national organization, to have an impact. The Alliance for Technology Access was really designed to enhance the effectiveness of the Disabled Children's Computer Group. I should say before going too far, that the Disabled Children's Computer Group--DCCG--changed its name--we've had a lot of name changes--and is currently the Center for Accessible Technology in Berkeley, and is known by that name at this point. Its change was the same reflection of why National Special Education Alliance became Alliance for Technology Access; it was really an explicit decision to stop serving only kids, and have a center that would serve anybody who wanted those services.

DCCG Ideology--Rebellion against the Medical Model

Jacobson: I think if you look at the history, that a lot of organizations, agencies, started out for kids and when those kids got older, the fact is that there was nothing for them as adults, so some organizations went on to help a broader base.

Brand: Yes that's right. Well, you know, the early days of DCCG were a reflection of the fact that there was actually a lot going

on, not necessarily specifically in computer technology, but in very broad ways through the Center for Independent Living in Berkeley for adults. There was really nothing happening in that same empowering way for kids.

I guess that's one thing I want to talk about a little bit. The philosophy behind all of this that was unique is that technology for kids had been a matter of prescription and medical--it was really under a medical umbrella, to the degree that anything existed at all. If you were lucky enough to have the resources or the coverage to be able to go to a place like Stanford Children's Hospital or the Rehab Engineering Center, you'd go and they'd evaluate you and assess you and prescribe this technology that they thought you should have. And [sigh] when we started DCCG, it was our idea that families, kids, adults, family members, knew what they needed, or at least what they want to accomplish. It wouldn't necessarily show up in an evaluation because if you didn't have the tools to work with, you couldn't necessarily demonstrate your capacity to use those tools, whereas all the rest of society was going to their local computer stores and buying whatever the heck they decided they wanted--sometimes making mistakes, sometimes knowing exactly what they wanted. People with disabilities were being told that there was a medical process to go through to get similar function. Yet another aspect of being a person with a disability was being medicalized.

It made no sense, so the idea was to say that the individual at the center of this process--whose decision about tools and goals was most important--was the individual with the disability--kid or adult. Our job was to pay attention to the desires that people expressed and to help provide, to support and facilitate that process, of that person getting the technology that they choose for the purposes they choose. That was a pretty radical notion and that was what the whole thing was all about.

Many of us who were founders of this whole process were those who had been victimized by the system which said, you know, you couldn't use this technology, you don't have the fine motor, you don't have the this, or you don't have the that. And you know, the whole point of technology was to say that all of those distinctions were no longer relevant because with the technology we could do things that couldn't have otherwise been done. But the value of self-determination, self-empowerment, a decision-making process centering on the individual and not around the therapist and the medical staff was what we were looking for.

Relationship between Families and Independent Living Movement

Jacobson: I think that's a very important distinction to make because the nondisabled world does not live their lives around the medical model, and the disabled community has always struggled to move away from the medical model. I wonder, when we talk about CIL not being very accessible to parents, how much that had to do with the fact that in order for parents to get services for their kids, they had to go through medical model. So perhaps the disabled community saw parents as a part of the problem.

Brand: Right, well, I think that's part of it, and I think families that are having to deal with CCS--California Children's Services--and doctors as gatekeepers to services for their kids, that's right, they get tainted with the medical model as their only conduit. But also, the other side of it, the other issue that comes to play in it all is that separation from one's parents and one's family is part of growing up and building a different kind of relationship with the world. It's a universal dilemma that all generations face, but I think it's a dilemma faced in greater degree for kids with disabilities growing up and becoming adults. The connection between parents and kids who have significant physical needs makes this transition even tougher.

I can't remember if we talked about this earlier, but I bet we did--there was this time in my life when I really thought Judith didn't really know where she stopped and I began, because her needs were so dependent on the adults in her life. The adults in her life were her conduit to the world, so for her to grow up and feel confident and confident on her own, and feel like a whole human being, I think there was a necessary need to separate out from her family.

In an environment like the independent living movement, which is promoting independence and promoting the values of giving the people the confidence to really go out on their own, it's hard to avoid having to, as a part of that, really create an arm's length relationship with family members because of the primary focus on independence for adults with disabilities. So I understand what led to the ILC estrangement with families, but the loss to kids with disabilities of access to mentors and adults with disabilities in an independent living environment, in the ILC movement, to me as I saw my kid growing up, was such a huge loss. Judith found mentors in other friendships because luckily we lived in a community where there were people with disabilities everywhere and there was access to friendships and relationships and all that.

Jacobson: In Berkeley.

Brand: In Berkeley, that's right--unlike any place probably in the entire world. There are very few places where people with disabilities are such a relatively large percentage of the community. So she still has some of that access, but when you think about communities where that isn't so likely to be true, yet there might be an ILC, you think about the power of that movement and its values on the growing up of a young kid with a disability who's surrounded by a family often without any knowledge or experience with disabilities. It's a great loss. There's a big price that was paid in taking that approach, but I also understand it.

I may have said to you that one of my earliest relationships with Judy Heumann was this major argument about me being this parent that she saw as way too overprotective and her having a philosophy that says, "When she turns six, you go take her to the local schools and leave her there and let them worry about what to do about her!" And me the parent saying, "Well, it's easy for you to say. Politically I agree with you 100 percent, but I'll be damned if I'm going to dump my kid off someplace where they neither want her, nor know what to do with her--and don't have an accessible bathroom and a classroom is up a flight of stairs and everything else." So it's an interesting dilemma, the relationship between family members and the independent living movement.

Also for families themselves, you know, here I was when my daughter became disabled: I consider myself so lucky to be living in Berkeley, which is where we lived. I thought to myself, You know, there's no place in this world where I can begin to learn faster than a place like Berkeley--going out, you know, over to CIL and working there, I did a little attendant work just to learn, and there were just zillions of opportunities. But again, most families don't have that.

Jacobson: And you happened to be very persistent and really aware of how important this would be to your daughter and your family, right? I don't know if other people have that.

Brand: Well, so it has to be encouraged. Exactly. And that's what you're saying, is that I was lucky enough to realize that I had a lot of learning to do. There were a lot of holes in my background in terms of my understanding at all about disability and my connection to disability until Judith was in my life and had a disability, so that's right, we don't have an institutionalized way to help people. Until we're a more inclusive society as a whole, it just ain't going to happen

unless it's going to happen in places like Independent Living Centers.

But again, I mean, I understand the need for that organization to really be focused on the needs of adults with disabilities and not worry about kids. But there's got to be more focus somewhere on kids and on families who, in expressing their values and attitudes about disability, are going to profoundly effect the way their kids grow up thinking about themselves and about disability in general. That's the truth and that's the reality that we still have to grapple with.

Well, you know, when we created DCCG, this was a critically important thing. The technology was going to empower people to be everything they wanted to be in their lives--to have dreams, expectations, and goals and to want to do any outrageous thing they wanted to do just like anybody else growing up wanting to do any outrageous thing they wanted to do.

Jacobson: You mean by way of technology?

Brand: Yes, exactly. All of a sudden, the technology allowed us to question the kind of diminished expectations that we were being fed as parents. I can't tell you how many people told me I needed to have more realistic expectations for my daughter. And all I could see was their wanting somehow for me to expect that my daughter would have no life--no quality of life--and no real future of value to herself or to others. I mean, they had no expectations. And it seemed to me that their most important message was, "Until you have realistic expectations, you're not being a good parent." That was the message.

Jacobson: Okay, so let's focus this a little bit.

Brand: Okay.

Technology Impacts Judith's Success

Jacobson: How did all those groups that you were doing impact on those expectations? How did it help Judith become more successful?

Brand: On many levels. Her success was impacted by the technology. On the one hand, having tools that enabled her to write allowed her to be a writer, a communicator. And having access to voice synthesis where she could hear, take down materials, and listen--auditory learning is her main way of learning--all of a

sudden she had a world of auditory resources that she could access through the computer.

But early on, I think one of the most powerful impacts was the way people looked at her as a computer user. All of a sudden they could imagine that she might have some intellect. All of a sudden they could imagine that she could have some competence and something that she could learn. Before that time, even though she was extremely interested in school, people could not imagine how she could learn because the tools didn't work for her. She couldn't demonstrate back in the ways teachers and others were interested, were used to seeing it; she couldn't demonstrate her capacity to learn. The capacity was there but teachers didn't have the tools to see that because they didn't have a way to unleash it.

And in terms of her peers, other kids in school, all of a sudden she was using a cool computer that was talking--it had a voice synthesizer--she was using this big keyboard and doing commands that others didn't understand, so she looked incredibly smart. In fact, I think in those early years, because people were so intimidated by the technology, she looked positively brilliant! [laughter] And I thought, okay, if people are going to have false notions of her, better let them err in the direction of thinking that she's the next genius--you know, she's Einstein--rather than expecting that she's nothing and that she has no capacity to learn.

So the technology gave her the accoutrements that she needed to be valued in school in an academic environment, and therefore gave her the kind of self-confidence for herself that translated into better achievement, as well. It made a huge difference.

And because of the work that we were doing with the centers and all that, she had a little bit of infamy, as well. People would come up to her a lot and say, "Oh, I've heard about you, I saw a picture of you, I saw the video you were in," or whatever, so she really got a lot of great feedback as a result of being part of this early movement. She felt very much a pioneer in the movement and realized that something really significant was happening.

There were so many levels where the technology changed her life very profoundly. I think in the early years we were pushing her into technology not because we knew whether she'd be talented at using technology or not, but just because there weren't other options--she had to become technology proficient. Today when I watch her, I see her as having a lot of talent in

the technology--as a matter of fact, talent that I never had. I see that she's just passed me by a mile. She uses the technology so comfortably and effectively and so much that it's the focus of all of the thinking and work that she does. It's a tool that has dramatically changed what her life is like.

Her own expectations for her life are pretty damn high, and many would argue ridiculously high, but I see her achieving things that just blow people away. They don't expect it, they've never expected it of her because of what she looks like. Because of how her disability appears on the outside, people make snap judgments, and then they operate that way. Most people tend to conform to the expectations that the world places on them, and if the expectations are low, you tend to function at a lower level. Well, the technology was kind of the prop that allowed her to really blow that all away and to do other things, so it's pretty remarkable.

Jacobson: It must have really impacted her self-esteem.

Brand: Say what you said again--I got "her self-esteem."

Jacobson: It must have had a big impact on her self-esteem.

Brand: Yes, enormous, enormous. You know, her contemporaries would come up to her: "Could I try that? Ooh, what are you doing?" It was just so impressive to people.

She got such good feedback from teachers and others as she would demonstrate her ability to use the technology. It really gave her a tremendous boost in her self-esteem, and as a result, she has amazingly high self-esteem I would say. She's pretty confident in her abilities and her skills. And so, yes.

I've seen that to be true for a lot of people--a huge number of people. She's not unique in that way. She's more unique than I wish she were. That is, most kids with disabilities--and adults with disabilities, even more so--don't have access yet to the technology that would make a huge difference in their lives. And that's the thing that still strikes me so profoundly. This is such an amazing leveler. It really levels the playing field for so many people, and yet most people still really don't have access.

And most people don't even imagine that they could use technology unless they can use it right off the shelf the way it comes. If there's any requirement, any need for any modification, it's hard for people to understand how to use it, or to realize it can be customized to one's needs. And for

people with cognitive disabilities, even more so, because people somehow assume that if you need a cognitive prosthetic device in some way--which is what the technology is--that the technology isn't available for you--that it implies a certain level of intellect. And it's not true at all. I think it's still part of the left over notion that you have to be so smart to use a technology. It's just a machine, and it can do so many things that otherwise are either difficult or impossible or time-consuming to do.

It's the same kind of prosthetic device that all of us use on some level. We use the technology to accomplish what we need to accomplish most effectively. But for many, many people with disabilities today, they don't have access to those tools to try them out, to play with them, to figure out what would work. So as a result there's a kind of division between people who are comfortable in using technology and those who aren't. There's a huge chasm in terms of achievement and expectation and self-esteem.

Jacobson: I think that would be a good place to stop for now.

Brand: Okay, sounds good.

Jacobson: Thank you.

V THE INTRICACIES OF PARENTING A CHILD WITH A DISABILITY

[Interview 4: December 3, 1998] ##

School Dilemmas: A Choice of Battles

Jacobson: We were talking last time about Judith and technology and I wanted to go back a little bit and talk about Judith's transition from school system into adulthood. I know you had some difficulties with the public schools, and we talked about that when Judith was in elementary school. Can you give us some idea of what happened after elementary school?

Brand: Yes, meaning middle school, high school, and community college.

Jacobson: Yes.

Brand: Yes, okay. Judith was in a pioneering class of a just opening middle school. Steve and I got involved in the planning for a new school in El Cerrito, which was Adams Middle School. It actually had been a school, but it was transforming its configuration--there were changes in the district. And it was a great opportunity to think about giving her a more integrated educational environment.

I think we talked about, to some degree, how we moved back and forth over the years between sort of the special ed environment in a standard school versus a fully integrated environment in that same school, moving back and forth between her needs for social environments and her needs for academic support--whatever. There's always been this kind of tension of trying to get some of both, and this concern that education for kids with disabilities has always seemed to have meant, or at least in these last years, kind of giving up one thing or giving up the other. Didn't we already talk about that some, Denise?

Jacobson: Yes.

Brand: Okay, so Judith participated at middle school, at Adams, and it was quite successful. There was a base classroom from which she moved throughout the day. This was the first time she was going to move among different classes. This was a pioneering idea that had kids together in teams, over longer periods of days, so it wasn't just forty-five minutes and then another teacher, and then another teacher. It was a pretty interesting experience and she liked it a lot.

I think actually in elementary school her interest in drama started and it really kind of flourished in that middle school and into high school, as well.

Let's see, the other thing--oh, yes, one of the dilemmas we had, which was always a dilemma for her--we seemed to struggle with this all the time--was the school was not fully accessible. And so during her--I think it was a two-year school, maybe it was three years--I've forgotten right now, but during most of that time, we were struggling to get an elevator installed in the school and about two months before she left, it finally was installed. So it is a more fully accessible school now, but that created some problems for her.

Jacobson: When you say she was fully integrated, what does that mean? Was that just academically, or was she able to participate in each particular activity, like drama?

Brand: I would say that there was a real effort to integrate Jude into the program across the board. It's not the same as saying that there was real success in every area; there definitely wasn't, but that there was an awareness of that need to do it. Also, because the special educator who had been Jude's teacher prior to middle school and was one of the teachers going to this new school, she brought with her some understanding of the importance of Jude also having communication with other kids with disabilities in the process--which has increasingly been held in disrepute among cutting-edge thinkers in special education, but actually I question that.

Jacobson: How?

Brand: Well, in other words, there's been such a push for integration of kids into the regular classroom environment, that the result of that, and this has certainly been the history for Judith in her secondary public school period, is that you're pretty much isolated from other kids with disabilities. The option is either to be isolated from anybody but kids with disabilities

or to be isolated from kids with disabilities. And the best solution for Judith, and I think probably for most kids, is some combination of the two. That is, if truly, you know, 10 percent of every class were kids with disabilities--or 15 percent or whatever the natural number should be--and that every classroom is like that, then there would be a sense of kids with and without disabilities learning together to some degree.

But I didn't experience that at all. Jude was one of the pioneers trying to--you know, one of the first ones, always, to be in a classroom of a teacher who had no experience with kids with disabilities, and who was usually very anxious about anticipating having Judith in her or his classroom. It was always a constant education of people with no experience with kids with disabilities.

At the beginning of the middle school, the difference was the special education teacher, who had a desire to see kids be a part of the whole program; nonetheless, also understood the needs of kids to have support together and to have time together, also. So it was a little more integrated in that respect than it would ever be again as things moved forward.

Judith went to two high schools--just to jump ahead--Pinole Valley High School, in Pinole, and part of the West County Unified School District, and then Terra Linda High School in San Rafael, where she finished high school. In both of those cases virtually every class she ever had was a class where the teacher was terrified, expected Judith couldn't learn, didn't want to have Judith in the classroom, and hid it or didn't hide it to different degrees. But always it was clear to me that Judith had a lot of educating to do as well as education to receive.

Jacobson: And we all know how much energy that takes to always be constantly educating the teachers and the administration, or the kids, or the parents.

Brand: That's exactly right. It takes a hell of a lot out of your own self-esteem and you know, it takes a lot out of you. Sometimes you have the energy to educate or fight and sometimes you don't have it. I don't remember how many times over the years we'd talk about choosing our battles and figuring out when you're going to take on an issue, and when you're just going to say, I just can't take that one on. And how hard it is to always be kind of in that position, where you are a new and unusual entity to everyone that you're surrounded by.

Jacobson: Here we go again.

Brand: And again. And again. [laughter] It's interesting, as a parent, to view my role of one from the early stages of being very interventionist on behalf of my child to really seeing my energy as really supporting my child to speak her mind and take leadership. Knowing when she needed support, or knowing when she needed support but didn't ask for it and didn't want it, and having to step back, and increasingly trying to help her to develop strategies and to be there for her but not to be there in place of her, or overwhelming her, which is so easy for parents to do.

Healthy Encouragement for Growing Up and Independence

Jacobson: Yes. Let's go into something that you said, because it's such a fine line about when do I rush in and be the advocate, and when do I pull back and teach my child and support my child to be her own advocate. And I don't know many parents who are able to do that with their own child.

Brand: Well, you know, there's probably pros and cons about where your child with the disability is in the family unit, too--whether that child is an only child, a first child, a later child, all the different things that come into play. Whether your child was born with a disability, gets a disability later, all these things affect the relationships.

For me and for us and our family, watching, having the experience with Michelle, and then the experience with Judith, it was interesting for me to note that I knew a lot more about Judith's life than I did about Michelle's. Michelle had the ability to have me in the dark, if she chose to, in a way that Judith didn't have, which meant I had more of a responsibility to have integrity in the way I intervened and didn't intervene. In other words, I was privy to information that if Judith could have chosen I wouldn't have or shouldn't have been privy to from her vantage point.

Jacobson: Like what?

Brand: Well, I'll tell you something that happened to Michelle that doesn't seem to relate to Judith but it really--well, there are a couple of things that happened. I'll tell you two stories. I think I might have told you this story earlier about Judith wanting to run away with her walker. Did I? I told you that

story, okay. That's a perfect example of if it were Michelle she would have just run away but Judith couldn't. I had to realize that Judith was out the door, even though she couldn't physically make that happen. I had to respect that she was running away. Do you know what I mean? And give her that.

With Michelle, another thing happened when she was in middle school. As you probably know, I'm a fairly activist type parent. I'm not shy about stepping in when I see something going on. Michelle had an experience happen that, as it turned out, wasn't monumental in her life, but it was monumental in the moment. She was accosted on a bus by a bunch of boys from her school who pushed her around and kind of fondled her and put her into a terribly uncomfortable situation. I didn't learn about it for about forty-eight hours, and when I learned about it, I learned about it from Michelle. She told me what happened and she said, "I couldn't tell you because you would have fixed it, and I needed to fix it. I needed to do it myself. I needed you not to step in and I didn't think there would be any way. You would have been so upset and worried that you would have stepped in."

And then she proceeded to tell me what she did, which was fantastic. It was absolutely unbelievable. She had been threatened by these boys, and apparently a lot of young girls had been and they'd all kept quiet: "If you tell anybody, blah, blah, blah." She went directly to the principal and reported it and stood up to those kids and really broke up this gang of boys and their terrible behavior. And reclaimed her own sense of self, because what had happened in this experience as she explained it to me, she said, "These boys were doing that, and I just sat there. It was almost as if I was paralyzed. I couldn't do anything." And it's not unusual for women who are victimized to have exactly that reaction. Then she felt almost like she had caused it because she hadn't felt like she could do anything about it. What she had to do was reclaim her control over her life and her body--first against these boys, and then in relationship to her family. She had to do it herself.

I learned so much from that--first it was a very sad experience for me, because it was so painful to me that Michelle felt like she couldn't have come to us and said, "This is what happened and don't you intervene, I've got to do it myself." She didn't feel she could have done that and we would have respected it, so it taught me something about how I needed to communicate and build my relationship and maybe change some of my behaviors with Michelle. But it also helped me understand with Judith, that her issues around growing up and

independence and separating from family--because of needing support, it doesn't get the same attention and she can't make some things happen. Michelle could make that happen in a way that if a similar thing happened to Judith, there would be an attendant nearby, there would be other adults in her life to keep her from taking charge on that level. And it was just an example of the kinds of experiences we needed to allow her to have.

The other thing that feeds into it is sort of interesting to me. It was on a sexual level, because there was a movie that we saw--you know the movie--it was a sexual coming of age movie of a young woman with CP from Mexico--Gaby, yes. And that also struck me because I realized, once again, when I looked at Michelle, her sexual awakening was not something that was shared with adults. I mean, I don't know the details. They're hers, just like my family doesn't know my details, and that's kind of the way it goes. It made me think again about Judith, how is she going to have those experiences she needs to feel full and have her life? And where do families intervene and where do families make judgments and where do families facilitate and step out and figure those things--and so there are any of a number of experiences that you see in the course of child-rearing, if you're thinking about it. You realize that modifications aren't just wheelchairs and you know, there've got to be ways to help kids with disabilities come into their own and to figure out the way that they can feel supported by their family and then also be free of their family, because they need that.

Jacobson: Is that something that can be addressed?

Brand: Absolutely. There is no curriculum on the face of this earth that I know of that ever talks about this stuff. I can't tell you how many issues around growing up in a family with a child with a disability, and then a teenager, and then a young woman, how many times issues come up that I can't figure out who to talk to. The people I talk to generally are friends who either can relate to it in some way or know us well enough to talk about it. But in the world of child development, the differences and the issues that come up--I mean, the closest you get to it, I think, in general, is the sibling stuff--how a nondisabled kid feels growing up with a disabled sibling. You see workshops and support groups around that, and that's good. There wasn't even much of that when our kids were young. I'm glad there's some of that, but that's just the tiniest amount of the whole thing, and I didn't have any of that.

Jacobson: What I think you're talking about is how parents can let go.

Brand: I think partly it's letting go. I think partly it's parents who don't grow up with disability, or don't have an understanding of the culture or the issues, and are trying then to be a mentor to their kids in ways that they have a lot of learning to do. I mean, again, I told you this, that one of the things that I was so lucky about was here I lived in Berkeley, I had access to an awful lot of informal learning--which is the way I learn best anyways--kind of on the job and with people. But most people don't have that; they are thrown --you know, I remember being so appalled to hear that most kids with deafness grow up in families where their parents never learn sign language! So these kids grow up speaking a language that they can't communicate with among their own flesh and blood. Now, tell me, what is wrong with this picture? I mean, it's just amazing. Well, I think that that's just a dramatic example of a zillion things like that that take place when a kid has a disability.

And it's not usual--it happens, but it's not usual that the family, the parents--one or both--have a disability raising a kid with a disability. The more typical thing, still today, is that it's parents without experience around disability at all raising a kid with a disability and trying to figure out how the same parenting rules apply.

And mostly they do. I don't mean to suggest they don't, but I'm just saying that there are subtleties in the difficulties around coming of age, growing up, building self-esteem, building independence, figuring out how to find mentors in a world that doesn't show mentors very often. All those things would support healthy growth, development, and maturity for a young person growing up with a disability in this world. We've hardly even begun to look at it.

So I think what happens to parents is they try their best to figure it out, like these are the stories of the ways that I've tried, understanding that I've had way more resources in learning. I've had lots of people to learn from. And also, my family has been very open--all of us have been open to teaching one another, and I think there is a very strong sense of respect for one another between kids and adults and the generations and so on. I think we've done better than many.

I can't tell you how many people have commented to me over the years about what a great mother I am because I'm doing the most basic stuff. And there's something about it, and I know people say that meaning well, but there are times when I'm awfully offended by that, depending on where it comes from because it's--well, how could you possibly be, you know, doing

that, having respect. It has a certain value judgment and connotations with it that are not very nice.

Jacobson: It sounds patronizing.

Brand: Absolutely, it really is.

And so anyways, as Jude's--getting back into the topic--as Judith is growing older, I'm needing to be aware of backing off. And I'm very scared about what role--you know, what she's learning, what skills she's getting, because she's been in a school system that's told her she's probably better off separated out. She's being told she probably can't keep up with the class--every semester, every class, every teacher. She's told, "Gosh, I don't know if it's appropriate for you to be here." She definitely is having trouble making friends. She's lonesome a lot of the time. She's having desires to do things where people think she shouldn't be, like do drama, like do dance. And people are saying that it's outrageous, or you know, we'll let you be here, but be quiet in the back. And that's a hell of a lot for anybody to deal with.

And I'm worrying about her being taught by the school district to sit there and be patient and not to complain, and Jude being too patient sometimes, in my view, and being willing to put up with stuff, and then having to say, "You know, Jackie, if you had this battle every day, you'd choose to pass on some battles--and how dare you decide what her battles should be," so there's all of that. And so it's tough and painful.

It wasn't until really late in high school that she got her voice in a way that made me feel [sigh] she's going to be okay. I remember one very potent example. She loved drama, as I told you, from elementary school, and she did all sorts of--she got into a bunch of different environments, sometimes with other disabled kids and sometimes with nondisabled kids. And when she went to Terra Linda and she started in drama--they did allow her to join drama, although I felt as though they didn't give her a chance to really do drama much. There was a little of this feeling, "Well, we've let her in here, what else do you want?" kind of thing. She would audition for parts and time after time after time she wouldn't get them. She'd be disappointed, but she'd say, "Well, you know, I'm still young, and they give the good parts to the seniors and you kind of have to wait your turn." That's what people told her, that's what she told us.

Then she got to be a senior and auditioned. And all these years she was taking drama classes and was really quite good. It was pretty neat to watch her work. She'd take it very seriously. She has quite a great inner life and fantasy life, and so she could get into parts. And she has the mindset for doing that, which I don't at all, so it was fun to watch her. But anyway, she auditioned in her senior year for a part and didn't get one. She didn't get a speaking part, and she came home one night from an audition, and I'd never seen her so upset in my whole life. She was just crying so hard, and started screaming, "What am I, a piece of furniture? I'm a human being, why can't she treat me that way," meaning the teacher. I saw her get angry in a way that I've never seen her get angry all these years. It made me sad, terribly sad, and also so relieved, that she finally had had her fill of being treated that way, and stepped forward.

She called for a meeting, she met with the teacher, she complained. She said she thought she'd been treated unfairly.

Jacobson: Were you at that meeting?

Brand: I wasn't. She was with an aide. So she wasn't totally alone, but she was on her own to do that, and it was hers to do. The teacher backed down a tiny bit and gave her a very tiny part. And this was the senior play, and it would mean rehearsals every day after school, rehearsals every night, every weekend kind of thing. And she basically had no role and she said, "No, I don't want it. I quit." And she dropped drama at that point.

It was a big decision in her life to say, "This isn't good enough for me. My time has more value than that." And it was a hard decision for her to make, but a really, really powerful one.

And now, the alternative would have been: mother goes to school, calls a meeting in the principal's office--and I probably could have forced something to happen. I don't know, I mean, I could have tried. I'll tell you, she needed to do that and it was a very powerful thing to observe, to watch and learn from.

The next big time when that happened was about the lawsuit that took place in college. I don't think we've talked about that.

Jacobson: No, but why don't we stop the tape and go to side B because I don't want to interrupt the story.

Judith's Powerful Stand ##

Jacobson: We're starting to talk about a lawsuit.

Brand: Yes, shall I go through that and then we'll come back to high school? Because the lawsuit happened when she was in community college.

Jacobson: Okay.

Brand: Shall I do that and then go back?

Jacobson: Yes.

Brand: Because it's related to another very powerful advocacy stand.

Over the course of her time in community college--again, it just continued to be this problem of finding--deciding on a class that she wanted to take, trying to talk the teacher into either allowing her to come in, or just deciding she was going to go in and work with the teacher in trying to make sure that she could participate fully and all that. So she got into this habit in the schools of talking and meeting with teachers before the class started, going to office hours--the idea being that people always were scared to have her in their classes and that if she could become a real person to them, and actually sit down and they could have a meeting with her, they would be able to imagine having her in the class. Just to calm them down and relax them a little bit. And that was a strategy that was probably pretty helpful.

Over the years--in fact, in middle school and in high school--she developed a little speech that she'd give at the beginning of each semester about her disability, welcoming kids to ask her questions and really meaning teachers could, too, but kids were usually more likely to approach her. She developed a lot of strategies to figure out how to work her way into the place that she wanted to be.

Sometimes she found situations intolerable. She had a horrifying experience in a course class where people treated her badly. She was so upset about how she was treated that she decided she wanted to quit the class. She talked with her aide and her family and said, "I want to quit." And we said, "Well, do you want to talk with the teacher? Do you want to try and make him change his approach?" "No," she said. "I don't want to. I don't ever want to go back. I don't want to see him. I

don't want to talk with him. I don't want to deal with it. I want to quit." And she did. That was her choice.

And there came a time with another class where she said it was even more difficult a situation, where she said, "I'm not going to take this, this isn't right." We went to see a lawyer to talk about it. And the lawyer said, "This is outrageous. Do you want to file a suit?" And Judith said, "Yes. I passed last year on this other person; it's time to stand up for myself. I've got to do it."

Jacobson: Could you tell a little bit about how it got started?

Brand: In that situation?

Jacobson: Yes.

Brand: Similar to every other situation, she had gone to meet with this teacher before the class. It was a class in musical theater/dance, and there were no prerequisites at all. And Jude knows every musical theater song, she loves theater, and she loves musical theater, and loves to sing. She and her aide went to see the teacher. In fact, her aide was a friend of this teacher's and had seen her in a social environment and had mentioned that Judith might be interested in the class, and they kind of arranged to get together. The teacher had said, "That's fine. We don't have serious dancers. It's one of these no prerequisite-type classes. It'd be fine." Jude met with her and it was agreeable.

The class met once a week and each week it got worse and worse. The teacher wanted Judith to be in the back of the classroom and she wanted Judith's aide to do something with her while the class was doing other stuff. And finally it came to a point where the aide was ill and Steve had to be her aide at the last minute to drive her to the class. They got to the class and the teacher stood in the doorway and said she was ill and not holding class that day. Steve came home with Judith. Judith couldn't see it because of her low vision, but Steve could see there were already some students in the class. But the teacher claimed she wasn't having class, so they came home and reported that.

I just had this feeling in the pit of my stomach that that wasn't what had happened. And so we called Judith's aide and asked her to call somebody in the class she knew, just to see if class had been held and, sure enough, it had been held. And during that class the teacher asked the class whether they thought it was fair for them to have a person with a disability

in the classroom, and essentially developed a lynch mob mentality in that classroom.

Jacobson: Oh, no!

Brand: It was pretty horrifying. I was glad that Judith decided this one wasn't okay. She wrote letters, she said, "I'd like to bring people from Axis Dance Comapny out to the class. I think it would be helpful for you to see how people in wheelchairs participate in dance. I would be happy to bring my adaptive P.E. teacher in if that would be helpful for you. But if I wanted to just be in a corner of the classroom with my aide, I wouldn't have to come to College of Marin to do that; I could do that in my own house. And I came to participate with the kids, and it's not fair that you're not letting me."

It led into a lawsuit, which I won't go into right now, because I want to get back to the other stuff. And it was very hard and painful and difficult. It was a very unpopular lawsuit. The press really massacred Judith. She was a subject of multiple talk shows, and the community really found it appalling that Judith should want to participate in this class. There was very little support outside of a small community. But that was a time, again, where Judith said, "This isn't okay, and I'm not going to let them get away with it."

These moments in time, I think, are times when parents--especially parents with kids with disabilities, especially parents with kids with significant disabilities--want to protect their kids. It's a parental thing to want to do. And it's very counterintuitive in some ways to step back. It's not easy to do. You have to just have a longer-term understanding of your kids growing up to be willing to step back at times like this. You understand your kid needs, not to suffer, but to build skills, and that these times are where the opportunities for growth occur.

What we have always said to Judith is, we're always here for you, we'll always be here. You don't have to carry the weight of the world--it's not your responsibility to educate the world. You can choose to pass on it, you can choose to take it on, or you can choose to ask for support from us, and we'd always be there. But the main point is that you choose, and you're thinking about it, and you're deciding what role you will and you won't play. That's part of being a grown up and our respecting that is part of supporting you to grow up, even though it may not look like support to somebody else.

I just think it's a hard thing for parents to do. The gut reaction is to just protect. And we've all experienced that. What happened earlier with Michelle when she had the need to do things on her own, she had other tools at her disposal to allow her to do it. She could cut a class and I'd never know unless she got caught and I got called. Judith can't cut a class without her aide knowing, you know. And so, not that I'm promoting cutting a class, but it's a part of life making these kinds of decisions and getting away with it sometimes and paying consequences sometimes--all the things that are part of growing up.

High School--The Search to Be Welcomed

Brand: Just to change the subject and to go back to high school, we continued to struggle with Judith in high school about to what degree is she in every class like anybody else and to what degree does she get some support. She needed support. She needed adaptive technology, she needed to explore large print, and she needed to explore developing audio modifications for things. They weren't going to deal with all those things in a regular class, so there were legitimate places where she needed a chance to figure out how she was going to modify the homework so she could do it.

There was really no system in the school to allow for that. There were special day classes for kids with significant disabilities, and I would say kids with the types of disabilities Judith had. They had a totally different curriculum and they weren't really integrated into the regular classrooms, except for a single class or activity. And I always thought it was funny because the attempt to integrate was very often in places where they'd have the least chance of making it, like recess [laughs] and lunch and P.E. I thought the places where kids with disabilities have the greatest disadvantage is where they thought of doing the integration. It didn't make any sense to me. It made much more sense to be in a more structured environment like a drama class or an English class, where there was a chance to modify and participate and so on.

Anyways, there was that option and then there was this other option where kids with learning disabilities would have a teacher that would be a one-period base for them and would help get them integrated. We made the choice to go in that second direction, knowing that these teachers were used to working

with kids who were just having little reading problems, and would feel uncomfortable about working with Judith. They were really terrible with her, as it turned out.

But the concept was right, which was that she needed some support and base from which to go out. We struggled with that approach, and we went through more than one resource teacher over the years.

We had some success and some lack of success. When she was getting near her graduation time we began to panic, because if Judith were to graduate, she would have no other resources from the vantage point of the public school system. She was planning to go on to community college and was going to need support to go to classes, and the public schools were going to wash their hands of her. However, if she didn't graduate she could continue to receive those services until she was age twenty-two.

So she was very close to graduation and in the last year we pulled her out of her regular program, with her concurrence. It was painful for her to think she worked harder than anybody in that school and she was not going to graduate, but instead she was going to get put into a special day class where she could begin to plan for community college and get the support she was going to need for the next several years. I'll comment a little bit later on about whether in retrospect I think it was a smart idea or not, but at the time it seemed like a very right idea.

Jacobson: I was under the impression that once a disabled child became sixteen, they were eligible for services from the Department of Rehab.

Brand: Actually, it's as early as fourteen, to tell you the truth, but that's very different from getting meaningful services.

Jacobson: Okay.

Brand: The game that gets played is the same game that Regional Center and the schools play: "It's your responsibility." "No, it's your responsibility, you pay for it." "No, you pay for it." And everybody wants everybody else to pay for services. We did bring in DR people while Judith was still in high school to start looking at future stuff, but they didn't really provide much help.

Jacobson: Jackie, at that time when Judith went to high school, you moved from the East Bay to San Rafael in Marin County. Did the issue of Judith's education have anything to do with that?

Brand: It was 100 percent of the reason why we moved, actually.

Jacobson: I thought so.

Brand: At the time Judith was in the Richmond public schools, which are now called West County schools. It's a very urban school district, a very diverse school district. And I'll tell you it's had a bad rap over the years because I think a lot of people have thought it was not a good program. Judith got a lot of great education there, and part of it, I think, is their experience with diversity allowed them to think about kids with disability as a part of that spectrum of diversity in a way that more homogenous school districts have really struggled with and have not been able to accommodate so easily. So it was with heavy heart that we made the decision to move.

I was pretty involved in the politics in that district because of the work I was doing with starting the Disabled Children's Computer Group. And I could see the handwriting on the wall. They were about to go bankrupt as a district, and the superintendent was going to be kicked out. We could see it all coming. I knew that services were going to be cut way, way back. And that's exactly what happened. The school district went bankrupt, the superintendent escaped and there were a lot of accusations. A person from Sacramento took over responsibility for the school, all decisions for the school district were made on the basis of fiscal issues.

I knew that under those circumstances, kids were going to lose services. Judith, who was a fairly expensive kid to educate, was going to lose services, so we spent a good deal of time visiting school districts. We decided we would rent our house--we had a house in El Cerrito. We would rent it out and rent a place in another district and start exploring other communities.

And while we were at it--our house in El Cerrito was up on a hill, very isolated, hard to get around. We decided it was time to move to a community where Judith would have better access to the community anyway.

We did something that we've done a number of times over the years: we called a bunch of friends to come together to think about this with us all together: Jude's friends, our friends, and family. And we actually started exploring ideas like

cooperative housing programs, the co-op movement and communities. We were asking people what they knew about different communities that were within commute distance of Berkeley, because Steve was going to keep teaching at Berkeley High School. We got a lot of good ideas and support. And then we embarked on this process of trying to find a good place.

We went to Alameda; we looked there. We went into Oakland; we looked there. We went not just to the schools but to the communities. We went to Benecia where Portia, a friend of Judith's, had moved. We looked at a lot of places and just tried to find a welcoming community. We decided we weren't going to be looking for a massive special ed department, we were going to be looking for a school that would welcome Judith.

What we found in most schools we visited is that when people get a choice, they basically say, "Oh, I'm sure we don't have the resources to serve you." And so it was a rude awakening to be told, "Don't move here," time after time.

Then we found this little school in Terra Linda, a public school in San Rafael, and they seemed to be welcoming. They said, "We'd love to have you." Jude said, "I'm really interested in drama." And they said, "We have a fabulous drama teacher." And in fact, at one point they said that, "Her class fills up so quickly that you need to sign up in the summer right away in order to get into this class, but you can't sign up until we have an address for you." We left that meeting so excited because there was nobody else who had said, "We'd like to have you," that we promised we'd have an address by the end of the week. And we did.

We rented a house, a little house. We said, "Let's rent a place really near the school and give up the school bus problems, and let Jude go to school from her home for the first time in her life." We found a little place just, you know, like that, and signed her up.

It was scary to leave the East Bay, because that's where we had built all of our relationships, but that's how it happened.

Jacobson: I have to make a comment even though I'm the interviewer. It really struck me as you were talking because that's what we did when we were looking at schools for David, who is not physically disabled, but has some learning disabilities. We found that after a year of public school kindergarten, where they couldn't deal with him or us, as his parents, I just wanted to go somewhere where we would be welcome. That's how

he ended up in a private school where we are more welcome--it's by no means perfect--but hearing you tell that story made me think that what Neil and I did wasn't so farfetched.

Brand: That's right, the need to feel welcome is so basic, but it's actually monumental.

Jacobson: Yes.

Brand: Monumental. And it's more monumental than what the specialized services might be or might not be. It's more monumental than a lot of stuff people do focus on. And it's also, in some way, not necessarily politically correct in the sense that, "What do you mean, asking whether or not--trying to find out if she'd be welcome, or he'd be welcome at a school? Because goddamn it, he has a right, and she has a right, and should be welcome anywhere."

Jacobson: Yes!

Brand: But the reality doesn't match that. And the importance of the educational environment--it always felt to us that that was a core place for Jude. It was a very important learning place for her--she yearned for a good school educational program. She had the interest in learning. And tremendous issues that got in the way of learning, so that a good learning environment was going to be so critical for her.

Jacobson: And there are so many battles to fight that once in awhile it's okay [laughs] to take the easy way out.

Brand: Right, right. I don't even know if it's the easy way out, but it's operating at this gut intuitive level, "So you like my kid? I want you to like my kid. This is a kid who's going to be in your school. Does it make you smile to think that she's going to do great stuff at your school, or that you're going to help her to or want her to and be proud to have her part of your program?"

There was just some feeling in that direction, as opposed to what we got in other places, which is, "We couldn't possibly serve your daughter. We don't have the resources. I'm sure you wouldn't be happy here." I mean, you know: "Not in my neighborhood, not in my school, not in my life." That's a hell of a battle to fight on top of everything else you have to fight.

So that's all it took. In that weekend we had rented a house. People thought we were nuts. We were just leaving?

And I thought, "Well, why not?" We weren't really doing anything more than deciding this is a place to explore.

They supposedly had a great drama department--that's the academic Judith wanted. She wanted great drama. It was a small school with small classes. And in the previous school she had been in, she had to leave class before the end of the period because she'd be so overwhelmed by the crowds. She was still insecure driving her power chair so they wanted her to leave early. The idea of being in a small school with wide hallways where she could travel with everybody else seemed like enough to justify making the move.

And as you might imagine, there were problems. The struggle between the special ed and the common ed we continued to deal with. Not everybody welcomed her that's for sure. But in fact, it was interesting, they grew to be very proud of her abilities and her skill, and when we as a family made the decision to pull Jude out of the graduation track so that she would continue to receive services at the community college, they were very angry. The administration was very angry at us. We had made a long-term decision, and what they wanted to do is graduate her. Well, they either wanted her out of their hair and out of their budgets, or they wanted her to graduate. I think there were both those feelings. And she deserved to graduate, she had every right to graduate, but it didn't happen.

VI COALITION BUILDER, SUPPORTED LIVING, FUTURE PLANS

[Interview 5: February 2, 1999] ##

Universal Service Alliance, 1995--Affordable, Accessible
Technology

Jacobson: Jackie, let's go back for a little bit and talk about the Universal Service Alliance that you started or helped to start in 1996, I believe.

Brand: You're probably right. The Universal Service Alliance (USA) was created out of a need that several of us saw to connect various communities to a common interest as the whole process of deregulating phone service was taking place in California and across the country. There had been new legislation--the Telecom Act--and many of us were really concerned about losing certain basic services, as well as the problems of an increasingly have/have not society based on those who'd have access to broad-band high speed data communications and those who couldn't even afford to maintain phone service.

Jacobson: What kind of services were you afraid that you would be losing?

Brand: I was worried that with the change in the climate in the country away from regulation where there would be fewer and fewer requirements placed on telephone service providers, that rates would go up and people with limited income would get thrown off the system because of phone bills that they couldn't afford. I was concerned about losing programs like Lifeline Services, again, for people with low incomes who can have a basic phone service at a reduced rate. I was concerned about losing or decimating programs like the Deaf and Disabled Trust, that provides accommodations in equipment and services to people with disabilities, people who are aging, and those who

have functional limitations who need specialized products to use the phone.

And then, more than even any of those things, I was worried about the evolution of a class of people using the Internet and using services that required high technology, and that we would be providing some services at a very low level to poor people and just those who were wealthy enough to afford it would have access to information technology through the Internet. I felt that it was going to exacerbate the climate between those of more and those of fewer means in the country. And here's a situation where it seemed to me that people with disabilities, though having some unique issues about access, in many ways were exactly in the same shape as many other communities who were also at risk.

This was an opportunity to try and bring disparate groups together, to go beyond our separate constituencies and try to come together around some common issues. It's always been something of interest to me to seek the commonality instead of the differences, and so I decided to take some leadership in trying to pull together a loose coalition of organizations that reflected both disability organizations and nondisability organizations, working together on common agendas. So that's what motivated me to get started with USA.

Jacobson: And at that time you were still working with the Alliance--

Brand: Yes.

Jacobson: --for Technology Access.

Brand: Not only that, but we created USA as a project of the Alliance for Technology Access. The Alliance sponsored the effort and helped to facilitate that process. Again, what I wanted to see was a disability-related organization being the leader in a broad coalition that also included people without disabilities, because I didn't see much evidence of that happening. And I thought, in the area of technology and communications we are pioneers. It's appropriate that we take the leadership, that we not just focus in the disabled community, but that we can, through our experiences in the disabled community, really be an inspiration and a leader in helping other communities to see their interest in this very same thing. So that was my thought--that this was a great opportunity for us to broaden people's understanding of technology for people with disabilities, while understanding their own interest in this general topic. That's what motivated me, and the Alliance was very supportive to that.

The other thing that generated enthusiasm for me was I have spent several years on consumer advisory panels with Pacific Bell, and so I have had the opportunity to learn an awful lot about how things were changing in the telecommunications arena in this country. I knew big changes were taking place in the world for everybody, and that we were either going to be a part of it or left behind. With a background of many years on the Telecommunications Consumer Advisory Panel of Pacific Bell [TCAP], I had some foundation and background to try and understand the nature of these developments.

I thought that understanding at least a little bit about that world--I'm not a technical person, but more a community person, gave me kind of the right combination of skills to try and launch this kind of coalition. If I were smarter about the field, I would probably leave behind a lot of people for whom it's just so complex to understand. But I am more of the mindset of trying to figure out what it means to us in our lives than, you know, how the wires are actually working and the speed and all of that. So in some ways it made me a good organizing person and I saw that as a good role for me to play. That's how USA got started.

And through TCAP, through ATA, through our contacts with a lot of organizations, we launched an initiative to build our relationship with other organizations. One of the very first things we did as part of USA was to contact various organizations up and down the state and organize some public forums. We asked those organizations to co-sponsor them with us, and we traveled to parts of the state to talk about what's happening in this field and what it means to an average person in a community, what's at stake, and how people felt about that.

So we did a series of these public forums and I got to know a lot of groups that I didn't know, from Hispanic groups and African American groups to rural community groups, Native American communities, and Asian communities. I got a chance to connect with a very broad coalition of people and met and began to identify some key leaders in the state--this was focussed very much in California--which then built up over these years to create a force of community leaders who could do some very significant work.

Jacobson: What about your contact with the disabled community? Did you have any connections with CIL or with the independent living movement in this?

Brand: Yes. I actually spent a fair amount of time with staff from the ILC in San Diego--Patricia Yeager, spent time with June Kailes, spent time with Betsy Bayha from WID, John Darby, and others. I relied on those people I knew to make contacts, then, with their own networks and their own community.

Jacobson: What about CIL in Berkeley?

Brand: What about them? In terms of USA?

Jacobson: Yes.

Brand: They got some information second-hand, but I didn't really have a good contact at CIL at that time.

Jacobson: What year was that?

Brand: What year?

Jacobson: '95?

Brand: Yes. In getting started, I wouldn't say that we reached everybody by a long shot. It was an attempt to bring representatives of various communities together, so if you asked me, "Well, how many of the Hispanic organizations did you reach?" It was a handful, but it was a beginning of people sitting in a room together: an organization which was thinking about the needs of Hispanic members of the community sitting next to somebody thinking about the needs of somebody with a disability, sitting next to somebody thinking about the needs of people in rural communities. We were really trying to cross a lot of these different categories.

It was just a very early process followed up with a fair amount of written material and faxing. There was less email, still, at the beginning stages because most of these communities were not online--which is exactly the issue. Trying to bring information about upcoming legislation, issues, meetings of the Public Utilities Commission that would be of interest to people. We spent time working with various community members who wanted to testify at the Public Utilities Commission over different issues, giving them some help in how that process works and trying to encourage people to speak up. We actually had quite a bit of success with people addressing the commission for the first time.

There was a young man in L.A. who addressed the commission there. He was a man in his twenties, I'd say, who used augmented communication to speak and he addressed the

commission through his technology and totally blew away the commission. At least two times after that over the next couple of years when I was at commission meetings there were references made to that day and that presentation.

The commissioners are basically isolated in their ivory tower and the people who address the commission are typically staff of the telephone companies. They see very few community people and few people with disabilities, so it was important to begin to open up that process, to have brought in members of the community. That was a goal of USA, to not only share information and get feedback, but to connect the community with the commission. That's the kind of work that we did.

We did have support for these activities from some of the phone companies that we went to and asked to fund it. Maybe one of the shining accomplishments of USA was to approach Pacific Bell and to negotiate an agreement in exchange for supporting the merger of SBC and Pacific Bell. USA played an important role in the negotiation that led to the Community Partnership Agreement. USA became one of eight signatories in the state to this agreement that provided, over ten years, over \$50 million in funding for technology projects that reached underserved communities.

Up to now Pacific Bell has never measured the penetration level of basic phone service in the disabled community because they said it was impossible to measure. They've measured it in every other community, but they haven't ever done any measurement of how well people have access to phone service in the disabled community, so there was an agreement in there relative to doing some research and study to evaluate and improve the penetration level of phone service in the disabled community.

There was the establishment of what's called a universal service task force that was put together with each of the signatories choosing participants, so that there's good disability representation as well as other representation on that body which is advising Pacific Bell on how to do a better job of penetrating all these communities.

There was a job commitment, and a commitment for a research component to look at how communities--underserved communities--are benefiting from and maximizing their access to emerging advanced technologies, issues of universal design, and how products are being developed to be designed for broader use.

So it was a pretty significant accomplishment that USA didn't solely do, but was a critical member of. That's the kind of thing that USA has been doing.

There were filings that we've done both in California and in Washington with the Federal Communications Commission around issues of access--the technology issues of universal design. We've done a lot of work along that line, writing briefs and so on. And so it's the kind of tedious work that's hard to pay attention to because it's not at the top of anybody's agenda.

USA Involvement in Pivotal Telecommunication Issues

Jacobson: How is USA supported and funded?

Brand: It's got a lot of good volunteer effort just to try and keep it going. Certainly Pacific Bell has been a major funder of some of the efforts we've done. We've had other phone companies--GTE--there've been a few others. We've also had a little foundation support.

There's something very powerful about a coalition as broad as this one. I love that when we were talking about access to new technologies and legislation in Washington, we could do a filing that the Urban League signed onto, that the California Latino Civil Rights Network signed onto, as well as World Institute on Disability and Alliance for Technology Access and so on. That appeals to me a lot, because my belief is that that's when you really can be effective, when you can broaden the support, and at the same time understanding that when there are issues of importance to the Hispanic community, a group like WID or a group like ATA would be there at the table as well, understanding our common needs and our differences and respecting that and really being there to support. So to me, that's what USA is all about--really trying to broaden that coalition around the issue of telecommunications.

The Community Partnership Agreement, which created a \$50 million fund and other important results, has led to requests for help and interest around the country to learn more about this model for how community leaders come together and essentially extract some benefit from a lot of loss in these industry mergers. Understanding that these mergers are happening, with us or without us, the question is, how do we reap the benefits that will promote good efforts in the

community? How will we promote some socially responsible actions as people are merging for financial and profit reasons?

Community Technology Foundation of California

Brand: The last part of what USA is up to right now and one of the most time-consuming roles I play right now is I sit on the board of the foundation that was created out of this merger agreement to oversee and govern the expenditure of the \$50 million and to leverage that \$50 million by bringing in funds from other people as well. The new foundation that's been created is called the Community Technology Foundation of California. There are about a dozen of us who comprise the board who are trying to launch this initiative in a way that will support getting the benefits of advanced technology into unserved and underserved communities. We will promote technologies that are universally designed to encourage broad use, and developing new applications that are important to underserved communities. It's an exciting new foundation, and it'll be interesting to see how it evolves.

It's been a lot of work in just getting it launched--creating it, incorporating it, and so on.

Jacobson: I wonder, is that money for--

Brand: It's California. It's a state foundation.

Jacobson: And \$50 million is quite a bit of money.

Brand: It sounds like a lot of money but if you think about it as \$5 million a year. If you think about the needs in the state and the size of our state, and you think about all the organizations that aren't even online--and there are community organizations who aren't even part of the conversation yet--and the efforts that need to take place, it's a pretty small amount of money.

Jacobson: Yes. Now, where did the money come from?

Brand: It came from Pacific Bell and SBC as a condition of their merger. What happened--

Jacobson: SBC?

Brand: Southwest Bell Communications.

Jacobson: Thank you.

Brand: Sorry, that's the entity that merged with Pacific Bell. There's a law that says in a merger in California, the benefit of a merger of a regulated entity, like the utilities, at least 50 percent of the benefits of a merger needs to accrue back to the people who support the phone company. And what typically happens in a situation like that when two entities merge, is normally they'll give you back a few pennies on your phone bill every month as a credit for that benefit. USA and others went to Pacific Bell and said, "Don't dribble away ten cents to everybody, it doesn't mean anything. Let's pull it all together and create something that will have meaning and do some good work. Let's take those pennies and nickels and dimes and create a fund that will support efforts."

And that idea then was submitted to the Public Utilities Commission. The commission liked it so well that not only did they approve it, but they basically said to Pacific and SBC-- Southwest Bell Communications--"Our approving your merger is contingent upon your signing this Community Partnership Agreement." So though Pacific Bell was interested in doing it, the Public Utilities Commission said, "You must do it."

And it was a great example of community groups coming together and saying, "Here's what we want from the benefits of that merger. We don't want credit of ten cents in every customer's bill, we want to do something significant." And we were able to pull that off.

Now what we do with that significant chunk of money has yet to evolve, and that's exactly what we're all working on right now. We're creating a request for proposal process for looking to disseminate some of that money, thinking about how we want to spend it--what our priorities are going to be. And the public at large in California should be watching it closely and be critical and be pushing it to be everything that it should be. Not that the members of the board aren't working very hard to try and do it, but again, it's a fund for Californians and it's a fund for those communities that we identified as underserved. It includes the disabled community, the Hispanic community, and all these different communities--rural communities and so on, and even small business communities--small businesses who are struggling in this era of big business/big mergers.

It's a pretty interesting little sidestep that I ended up being able to take, and just another example in my life,

really, of an opportunity which appeared in an area I would never have expected to be involved with.

Jacobson: I'm going to turn over the tape before we start on another topic.

Judith's Search for Adult Life of Quality

Jacobson: Let's get back into what you are doing now, besides your continuing involvement in the USA. I know for the last several years, you have been involved in creating the Independent Living Network. When did that begin?

Brand: It was formally incorporated on April 1, 1997. Well, that's one date I do remember. [laughter] April Fool's Day. It was growing in my mind for a long time before that.

As Judith was approaching adulthood and we were looking at what was out there for her, it was just very hard for me, or her, to have a picture of what her life would be like. I was getting more and more concerned because there were few programs that seemed appropriate for her and fewer still that would consider her participation. It was clear to all of us that Jude needed some support, but it wasn't clear support to do what--what she wanted to do. And as we looked around, we didn't see models of things that made sense for her.

Jacobson: What did you see?

Brand: Well, Jude and I spent a couple of years just kind of exploring the world of adulthood, trying to go visit places and people to get a feeling for how people live and what people do. She really didn't have a concept.

She had been going to community college at College of Marin after high school and enjoyed a lot of that--did some stuff there--but it wasn't clear--like with a lot of young twenty-year-olds. I mean, I didn't know what the heck I was headed for, myself, but I did know I was headed out my parents door and I wanted to be on my own. Jude couldn't imagine living away from us. She said that. She just couldn't imagine what that would be like. And that was very scary to me, and so we just started calling people and visiting people and places and we actually put together a spreadsheet. As she discovered

things that seemed great to her or terrible to her or important to her, we started trying to capture it on the computer.

Jacobson: Like what?

Brand: Like for example what it was like to get around in the main downtown of a community? And what was important there? And how hard was it because of Jude's blindness and use of the power chair--how straight, how level did places have to be? How hard was it to get to different places? What are the things that were important in her life that she wanted to do? And how near did those things need to be? How was she going to get around? What was transportation going to be like? What was it like to live with a lot of people? What was it like to live by yourself? Was that possible? What did it mean? For somebody who was doing it, what was that person's day like? And could Jude imagine her day like that? Would she want to go to school and live on campus? And what was it like to live in a dorm if she wanted to do that? What was it like to live in a small town versus a big city? Just zillions of things like that. Just because we didn't even know where to start, we just started by calling people that we each knew and visiting.

Jude spent a lot of time with a friend, Portia Lemon, who had been wanting to be independent since about the age of three, I think. I mean, I just remember Portia as a young girl, just always having such a drive for her own independence --which I didn't see that Jude had. And I thought that was so interesting. Jude and I went together, or she went with an attendant--trying to separate myself out from the process some, too. She went to places like centers where people were working in programmatic ways around independence, like there's a program in Albany--or San Pablo, actually--that serves people with blindness, helping people get independent and on their own, and saw what that program looked like. She went for a couple of weeks to the program at the School for the Blind in Fremont in the summer time, which was like an independent living program.

Throughout her childhood, Jude had gone to many summer camps, but always was miserable and homesick, often wanting to come home before it ended. Every year she would say, "I think I can do it this year. Let's try," and so we'd try another camp and she'd get just bereft and lonesome and cry through the whole week. She'd survived a lot of them because she was forced to, but it never ended by her feeling confident that she could do it and even enjoy being on her own. Up until this point, the camps were Jude's only experience away from her

family. Now she had to figure out where it was that she wanted to go, and how she wanted to live her life.

I just felt as a parent--and I think parents feel this, is their kids--you know, some people feel it early and some don't feel it until later, but from the time Jude was very young, I was really trying to imagine what her life would be like as she got older, and what skills and what support I could be giving her. Not being a disabled person myself, I was lacking sensibilities, I was lacking experience--like experience of lot of the things that she was going to need to find.

I don't know if I'm repeating myself. I think I must have told you about the meeting with parents I went to at San Francisco State that had been pulled together by an OT who had worked with families through the years and brought them all together because they all had adult kids at that point. She wanted to know how things were going, what the kids were doing as young adults. Did I mention this?

Jacobson: No.

Brand: Okay, this was the day Independent Living Network started in my mind in a formal way. Parents of young adults with disabilities were invited to a day of discussion. I was the parent of one of the younger of the group because Jude was still, I forget, late teens maybe. Most of the others were in their early mid-twenties to late twenties, early thirties, and so on. And basically this OT had gone back to those families she remembered as the movers and shakers when their kids were young. These were the ones carrying on for good education, for mainstreaming, for least restrictive environment, or for whatever it was. These were the families she had remembered as being really very activist families. She was interested to hear what life was like in adulthood for the kids from the parents' perspective.

I went into that meeting, and the way I remember it and have described it a million times--I'll just never forget it, I felt like I was walking into a room of concentration camp survivors. They were exhausted, depressed parents whose kids were mostly sitting home, watching TV, doing nothing. They were still periodically fighting to get access here or there, but their kids did not have lives. And it was the most horrifying meeting. I don't know how others felt about it, but it totally changed my life because I realized that was where Jude would be heading unless we did something to change it.

How could you, you know, struggle, struggle, struggle through all these years and you finally burn out and your kid has no more advantage than if you had, you know, put them in an institution somewhere. I mean, it was just so amazing to me.

I called some parents of older people that I knew, like I called a woman by the name of Sue Sweezy, who's down the peninsula somewhere. I said, "Sue, I just had this experience," and I told her about it. And she said, "You know, I don't know why nobody ever told us we had to save some of our energy because the biggest fights were going to start when public school was done. That's when we all were burnt out, and there is nothing left to fight for, and all of our kids are sitting at home doing nothing."

Now, I'm sure this is not 100 percent true, but it was true enough to see in this room of really caring activist, sensitive, good value parents, who felt so defeated and beaten. Parents who felt their kids' lives were so diminished and that they hadn't been able to either give them the wherewithal to go out and fight, or fight the system adequately.

I realized that we had to begin right away for Jude to be thinking about the rest of her life and for us to look at what role we could play in supporting her so she could get where she needed to get to. I began to have these terrible fears about dying before it was all figured out--you know--I think this is typical parent stuff: Oh my God, I can't die, my kid isn't happy yet.

But that was a transformational day for me. I realized that much as technology was very important to Judith, it had to fit into a life that we needed to be thinking about and planning together. Finding how we could provide some of that support for her, and how we could help her to grow, for her to have expectations for having a good life, and figuring out what that would mean for her. What was her good life going to look like? So we started, as I said, doing a lot of visiting and meeting, going to programs, talking to people and getting ideas, and talking to people who were running programs and talking to our typical agencies--the Regional Centers, the Department of Rehabilitation, and just various parent centers like Matrix in Marin--and other parents.

I went to a lecture by a parent who was talking about supported living for her son and a program that she had created in Santa Barbara a year or two before and how it was working. It was a very exciting presentation because I finally could begin to picture how Jude could move into her own life apart

from us, with the support she needed to feel safe, but directed by her in a direction she wanted to go. I could see in this concept the philosophy of supported living and the values of supported living, kind of the kernel of creating something for Jude.

So I brought her to a couple of meetings, and she got to the point of thinking, "That sounds good. I can't imagine what that would be like, but it sounds like I might want to live on my own." And that was really all I wanted to hear from her to give her some next tools.

I contacted the Regional Center, which is the agency that will fund supported living, and it's in its very early stages, so there's still some money around. There are very few organizations that are doing it because it's not financially very viable, but what I learned was that there are a handful of parents in the state who have created supported living environments on their own by self-vendorizing. In my case, we created a little nonprofit organization--and could make it work because we didn't have the overhead of an organization we were funding and also because we put in all the volunteer labor into it. We could get a system in place, and there are about eighteen or twenty parents in the state who are now doing that.

Jude and I started meeting with the Regional Center because we had to first convince them that, one, Judith was interested in that, which was easy, but that, two, she was capable of succeeding in a supported living environment, that she had enough skills to do it. By law, that's not a fair question to ask, but by the way they behave, it's exactly how they function. We began the process of discussion and that led to writing a proposal for supported living.

It's required that you have a program design, so I spoke with all the parents I could find who were doing some form of supported living, figured out what pieces would seem right for Jude and what pieces would not, put together my own program design, and submitted it and negotiated with the Regional Center. At the same time, I started the process of creating this new organization, because I was trying to separate it out from myself personally as a parent. Even though I would work in that organization, I was trying to really create a system that would grow with Judith and certainly outlive us.

Supported Living: The Independent Living Network, 1997

Jacobson: Jackie, could you clarify or talk about supported living as compared to what else is available?

Brand: Yes, I'll give you a continuum to give you a flavor for it. On one end of the continuum would be independent living. That would be a person living on their own, purchasing whatever support they might need, maybe hiring an attendant and so on, but being pretty much on their own. Further to the other side of the continuum in supported living would be group homes, further would be nursing care, further would be, I guess, institutionalization as care giving. But in terms of what the realistic options are for somebody in the community, group homes are a typical plan that's offered for people who aren't able to live independently but can live in a group situation.

Jude had the desire for independent living. She isn't somebody who likes to be one of six people going bowling on Wednesday night, you know, because that's what the program is doing. She really has a pretty clear picture, as it turns out, of what she wants her life to be like. But she needs a fair amount of support in doing it. She isn't able, for example, to get food by herself; or toilet, even, by herself; get out of bed by herself; or see enough to travel by herself without some support because of blindness--so she needs a fair amount of support, but she needs to direct it. And she doesn't need people to tell her what her life should be like; she just needs a lot of help in having her life as she'd like it to be.

In group living, you typically live with a group of six people and there's a house parent that lives there that kind of directs things you do and kind of organizes program for your life. In independent living, you're living on your own without any particular support, except if you have--in Judith's case, if she were in an independent living situation, she would hire attendants for attendant care, pretty much quite extensively.

In supported living, she's really determining where she wants to live, how she wants to live, and what she wants to do, and she's got staff support to help her with the pieces that she needs help with. Staff is funded through regional center. And that's available for people who are qualified to be clients of regional center, as she is.

So in her case, she lives in a home currently with two housemates. They're actually looking for a third housemate. But she's on her own quite a bit--there are staff there who are

her housemates, or other people who come in who are available to her as she needs that help. They don't determine what she does, but they support her in the ways that she needs and, increasingly, in the ways that she articulates that she needs. In the earlier days she had to learn a lot, but now she's directing more and more of it.

Jacobson: Can you give an example of how she might use staff support?

Brand: Yes, let's see, I could pick today, any day, Thursday.

Thursday mornings she likes to go to the Civic Center because there's a farmer's market and she needs to get produce for the house or for her food for the week. She has somebody cooking, and they would sit down and figure out a list, and together they would do that. And somebody would drive her to the farmer's market and would do the attendant support of getting out the money, describing for her the stalls--what's there and what the prices are--and help her to figure that out. They take out her money, and tell her how much money she has left if she asks that question, do the shopping, take it home, and have that person put the things away.

Then she goes to a class in Oakland. Someone will drive her over to Oakland and will take notes in the class. It's a cool class at the Oakland Senior Center called Wisdom Traditions--Chinese, Native American, and Jewish stories and wisdom. They would take notes, that person would come back and help her to figure out how she's going to get the support she needs over the week to do the homework and reading.

She'd then take what they all figured out and she'd pursue it and follow through on it. That's kind of what I mean--there was a time when she couldn't hold it in her head until she got home. By the time she got home it was gone from her head. She does have a memory problem, but she's getting better and better because she's recording stuff and she's growing in her capacity.

She'd get home and then she's got to make sure somebody's preparing her meal, and then she goes to meditation that night, on Thursday. That's her day.

She's increasingly taking more and more responsibility for identifying her own medical needs, but there was a period where even time and months was just a tough concept for her. Now she's got it and she's keeping a medical journal. That's evolved through this supported living, so it's a growing, changing situation. What I see is, just like her alternative

keyboard that gives her that extra little support to be able to use the computer, this is the kind of support that's getting her in the middle of the world and helping her to evolve her own style and desires and so on. So I have a very, very strong and positive feeling for supported living as a concept, even again beyond disability.

I have friends who have kids without identified disabilities; they're just lost young kids who don't know what the heck they need or want. And what I think is that they need support. Not forever, but for a while they need somebody there as a friend and a mentor in a couple of key places to help get them through, just the same as Jude, only more obvious for her. For her it was more critical in some ways, but I look at their lives and I look at her life, and I think, boy, they're floundering and they don't have any disabilities per se. I look at the stuff she's having to deal with and she's having a fabulous life, and what's the difference? That's the difference. So it's to me very interesting.

I feel that, in general, having now raised two daughters that unless you're on a very typical track, which is high academic achiever going to college and going into professional life, there are very few support systems in our culture for growing up and having different options. And if you don't do it exactly like that high academic achieving professional middle class type, you might make it and you might not.

In Jude's case, this concept of supported living just totally fit, which is she has people--who are her age, by the way--working with her--because those are the people she chose. She's hired and identified the people she wants around her, and she's getting that kind of support to help her think about and get involved and test out new things--the kind of stuff that otherwise wouldn't have happened. She feels like she's having a great life and she is. I don't see it as exclusively disability-related, although I think disabilities exacerbate and create extra opportunities for needing some support. Certainly some of the issues she has really lend themselves to support, but I just see her blossom with that support.

I see the needs for support changing and evolving over time. For example, when we first started, she had people with her pretty much twenty-four hours a day. Now there are times when she's on her own--not for long periods, yet, but it's growing, it's changing. Whereas somebody hired to do supported living would accompany her everywhere, now, for example, the meditation class she goes to, different people from the class come by and drive the van and take her out. She doesn't go

with any support person. People there know her now and she feels comfortable. She knows how to get around. She's done the route now and knows it, so she can do it on her own and she's happy to be doing it on her own.

Jacobson: Now how did that happen? How was she able to form those relationships with people that were in her meditation class?

Brand: It took a while. She went there with her supported living person, that supported living person has in her head that responsibility for facilitating relationship-building, so Jude was getting the support and the facilitation and then that person was backing out and letting that happen. What happened was that this supported living person who was doing meditation with her ended up having to do something else on Thursday nights, and she said, "I can't do meditation with you, Jude, I can't come on Thursdays." And so it came up at the medication class--I guess Jude mentioned it, that she wasn't sure quite how it was going to happen, we'd be looking for somebody else--and the class thought, well, wait a minute. Somebody said, "Gee, I could help. I could come fifteen minutes earlier." And somebody else said, "Yes, I'd be happy to do that, too," and so from looking to hire somebody to replace that person, we specifically decided, no, no, no, this is good, this is just what we want.

So now it's a situation where somebody comes to the house, gets the van, takes Jude, and then brings her back. And there's somebody there when they return, so if there's any dilemmas with the van or the lift or anything... But again, I think it's that initial support that gave Jude the confidence and led that to happen. It would never have happened otherwise. And that's a great example of what supported living is all about, building up the natural supports and relationships that are so hard to build.

Jacobson: I think one of the barriers for people with disabilities has always been the financial issue, so I'm wondering about the financial--

Belief in Judith

Jacobson: Jackie, we were talking about the financial aspect of supported living and you were saying that the staff is paid for by Regional Center.

Brand: Yes, right. The funding is inadequate for most organizations but works for a parent-vendored program because we don't have all the overhead of an agency. My experience in using it in the budget as a parent with a small organization that has no overhead and no salary to the coordinator, myself, is that it's doable. The things that are included in funding supported living are the staffing for supported living, expenses like, for example, if Jude wants to go to the theater--as she has done several times this year [laughs]--the cost of an attendant to go with her, or supported living staff, is covered in that budget. Not Judith's cost; she has to pay all of her own personal costs--rent, food, entertainment--all those things, but the cost for that support to make it possible is covered.

Jacobson: Now where does she get her own finances?

Brand: She gets SSI and she gets IHSS--In-Home Support Services. She's making it by being very careful, and for the first time in her life, the meaning of a budget is clear. I can't tell you how many transition practice exercises we did. But you know what? When you live with your family and they're doing the shopping because you're not going to be doing it, you don't have a clue; it doesn't mean anything, it doesn't have to mean anything. And now she's very aware of and careful about expenses.

She started out doing a lot of organic shopping and she's figured out how to cut her costs and that's why she goes to the farmer's market on Thursday now. She loves to go to Whole Foods, too, to shop, but it's very expensive and she can't always afford to do it. And she's really watching her budget very carefully, but the financing for supported living itself is pretty well covered.

Through funding for supported living we are able to buy liability insurance, health insurance for some of the staff, we have put in security systems in the house, and all the staffing is covered. So it's not heavily funded, that's for sure, it is modestly funded. Is this a replicable model, or is it something that's working because I'm putting a lot of money into it? And the answer is, no, I'm not putting a lot of money into it. I do slip her some groceries, now and then, [laughs] but parents do that kind of stuff, you know! When my parents come they still bring me things. I hope they always do!

Jacobson: Yes, that's what parents are supposed to do.

Brand: That's right. But is it working essentially? I'd say yes--carefully. I spend a lot of time on making it work. But I

believe this system can work and I believe that there's no comparison--I can't think of another approach for Judith that would be more supportive to her needs and desires than this situation.

She started living on her own in supported living October 1, 1997, so it's been almost a year and a half, and the changes in her have been absolutely remarkable! And the change in all of us has been remarkable, because I do not live my day worrying about Jude anymore. I look forward to my time with her--and she does make time for me, which is nice, and then sometimes she says, "It's been great, Ma, but I've got to get home," and that's wonderful.

And she is, you know, growing and appreciating her own ability to be who she wants to be, and has great days and miserable days like any other twenty-four-year-old. It's absolutely clear to me that she has a good life, and clear to her. If you had said to me two years ago that today she'd be in this situation, I would not have believed it. I think I had a lot of belief in my daughter, I mean, I have always been very proud of her achievements, and she's just a great person. I just happen to have a huge amount of respect and regard for her as a human being, so it's not that, but she did not have a chance to demonstrate who she was, even though I thought I was like the most proactive parent pushing her toward independence.

It's not until you leave home--and Steve Hofmann once said this to me--that you grow up. And it doesn't matter what home --how wonderful or how horrible home is, it's just true that you just don't have that chance. And to have the kind of transition that she's has with the supported living has been phenomenal. I don't know how it's all going to end, but I don't need to know, it's evolving very well.

The other thing about it was that when we first came to the decision of trying to promote supported living--she wanted to do it, we were going to write the proposal, and all that--I had in my mind that it might take her five years, ten years, to make that transition. At the time I said to her, "I don't really care--it doesn't matter what the timeline is; it matters that you're moving in the direction of your own independence and your own happiness. If it takes you a day, that's fine. If it takes you a decade, that's fine, too. You'll know as you're doing that." I was very prepared for this to go much more slowly than it did. And I don't think it was because I wanted it to--I just was trying to be realistic and to realize that there were going to be a lot of things to figure out.

We bought a house that Judith could rent with housemates. That was one of the things that we did that most people don't do. Most people rent a place. But we decided to purchase a house that we could then modify to increase Judith's independence. When we first started working on the house, she would come spend time there planning with us and helping to think about how the bathroom would get modified and so on. Then she started spending time there with attendants or support people. And then she started to move things over, little by little, as we were working on it. Then she started spending a night there now and then, not ever with us, but with somebody else, as in that's her place, not our place, not an extension of our home. We thought that might go on for months like that, and just slowly evolve, but very quickly it evolved to living there with housemates full time.

She had a couple of hard months. Maybe the first month was very exciting and she loved it and it was very thrilling, and then she began to feel homesick and she had some struggles. She was never very good at articulating that, but she got damn good at it because she had housemates to articulate it with who were helping her with it. Those people who were providing her support were saying, "You know, I get homesick sometimes, too, and it's okay to feel that way. You know, so here's what I do when I feel rotten. Let's go out and have some ice cream," or whatever it was.

They helped her work it out to the point that she would begin to call and say, "I had a hard day, but you know, Susanna and I talked about it and she told me this great story of something that happened to her, and I thought to myself, I can get through this."

She began to have an awareness and understanding of other people on a level that she'd never had, as well. She had been very self-absorbed about what her own needs were, which is something we do with our families because we're kids and the parents are the ones thinking about you and you're the one thinking about yourself. She had to evolve from that. I will never forget the first time she called me and said, "Man, was I--" --I forget what she--she didn't say "I was a bitch," because she doesn't use that language. I can't remember, but she said, "I was so snappy with Jessica. I just don't know what was going on with me, but I apologized to her because I was in such a rotten mood and it was really unfair." I had never heard her articulate that before, and I thought this is an indication of what it means to feel responsible to other people, and a part of a different community, and not just about what's happening to me--and it's fabulous.

Nourishing Environments for People with Disabilities--
Discussion of How They Grow

Jacobson: Is that something that you were concerned about as she grew up --her being self-absorbed, knowing that in the real world she'd need to relate to other people? When you realized that, how did you deal with it?

Brand: I worried about it a lot in the sense of how you build relationships with people if you don't have something to give as well as to receive. It's a two-way street, and yet, how do you also balance out the needs you have? You have some very specific needs that you understand, and make sure you have met, so it's not to suggest you don't have needs that are very important and legitimate, but where is that balance?

When she was a child, I remember issues about waiting--waiting for attendants, or waiting for the teacher to get to you when they were done with everybody else in the class--and I remember feeling, don't sit there and wait. Speak up! You have rights, too. And then the other side of it being, you're not the only one in this world, other people also have rights. So I think it's a parenting thing that you worry about particularly in parenting a child with disabilities.

Jacobson: Is that something you would talk to somebody about, like an OT or a PT, or is that something you'd put in an IEP [Individual Education Plan]--to say the goal would be for Judith to interact more and become more aware of what's going on around her?

Brand: Yes, it's a complicated answer. Yes. That's true that you put that in the IEP about interaction. And no, I wouldn't put in the IEP anything about not wanting her to be too self-absorbed because it's the opposite problem in school, in general, which is knowing when to stand up for yourself, so the issue of being self-absorbed would be something I'd be more likely to talk to a friend with a disability about.

I remember two people I've spoken to about that over the years. Nancy Kaye was the first person, way back when Jude was young, because Nancy had been somebody who had had multiple hospitalizations and her world was so defined by the hospital environment--and what it meant for her as she was growing up and building friendships. And just hearing about people's experiences, not necessarily that what happened to them was the most positive thing, but what they learned, what they took from their childhood experiences. I think parents who are not

disabled who have disabled kids are missing an important experience--I said this earlier, but here again, these are the times when you really have to go to other people. It's not an OT I go to about it; it's not a professional that I'd go to. I mean, somebody who happens to be a professional I wouldn't hold against them, but it's having had the life experience and understanding--either how it felt that you didn't have friends, or you figured out ways to have friends, or what were the different experiences that you had.

And in Judith's case, because her physical needs seemed so huge, it was such a daunting barrier. It was like a fence all around her all these many years--it was so hard for anybody to break through. Certainly it was hard for her to open her gates and welcome people through. It was very hard. She was focused on staying upright, literally trying to see what everybody else seemed to be seeing--where's the room for thinking about other people?

I think she needed to grow up enough to get solid in some of those areas, to have room in her head and in her spirit to care about relationships, for them to be important enough, because she's figured out her basic survival. But now she's in a situation where she can't assume everybody's life is revolving around her anymore like she did at home. Now somebody will say to her, "I know this is what you want, but you know what, I'm busy now and you know, go jump in a lake," you know, just like what happens in life sometimes.

I might call her and ask, "Well, did Jessica do blah, blah, blah?"--something that we had all talked about she was going to do--and she'll say, "I'll check with her, but you know, I think this isn't a good time. She's busy now," or, "I'll talk to her when the time is right." She's got a sensitivity about how and when to approach people and about what, knowing how to be sensitive and therefore knowing how to be a friend. I don't know how typical or atypical she is in this; I just know her.

People will sometimes say to me, "Oh, gosh, it must be so hard for you to have her living away--there's nothing like being at home. You know, nobody's ever going to love you like your parents." I just laugh because I think Jude couldn't have the life that she has living if she was living at home. I see the difference and it's enormous.

It's not because we don't love her to death--we do, as parents love their kids--but it's that she needed that other environment to grow and to nourish herself and really establish herself as a separate human being.

Jacobson: Do you have any plans to expand the network?

Brand: Well, I'm very ambivalent about it. I keep saying to myself, think small. I'm trying not to think in terms of another career, essentially. On the other hand, there are two things I am doing. One is trying to promote the concept in various places and speak on it and meet with people and so on, because I just have a very strong and positive feeling about it. I mean, people need to know. Jude's a great example of what's possible, because people would not think she'd be doing what she's doing. I've actually encouraged her--she and her housemates have done some speaking, too, which is the most helpful of all.

Then I feel that I need to be open to the idea of trying to help somebody else get going at some point. That might be another person, it might be somebody in Jude's house, another person in supported living in her house. The original idea was that the household would have two people with disabilities and two people without disabilities; not necessarily two people who needed supported living, but it could be. But it's been hard to find somebody. I'm kind of at the point of thinking, well, they should just rent it to whoever they want to have live with them and not worry whether it's a person with a disability or not. There's a piece of me that just hates that because it's so hard for people with disabilities to find great living arrangements. There's a lot of discrimination and not many options out there.

It isn't a career goal that I have--for sure, I really want to slow down on my career goals--it's just one of those things where I just see that there's funds right now and it's an opportunity to really make a big difference. So I'll be open to seeing it stay very small like this, or seeing it grow just a little bit, too.

Future Plans

Jacobson: So what are your future plans?

Brand: Well, I'm pretty busy in the present and so my future plans are to try and do less. I'm really trying to be a little bit more thoughtful and less active in my life. If I did that, I think I might want to do some writing. I might want to write about some of these things. One immediate thing that's needed is for someone to write a practical manual of supported living: ideas,

the first year in the life of a person going through supported living from the vantage point of Judith, from the vantage point of supporters, and the vantage point of the parent. I think it would be so helpful to do that and I keep toying with that idea. I just don't have time right now. I'd like to try and capture some things that I think haven't been written and would have value.

I get asked a fair amount about writing about some of the other things that I've done or that have happened, but I'm not so interested in just a record. I'm really more interested in --I mean, I'm sure it would be good to do, but I'm not inspired by that particularly. But I am inspired by the idea of trying to help figure out how to replicate this idea of supported living: what are the turning points and what are the decision points. What are the tough things to prepare for? What are the examples of design plans that people could use? Somebody who's a little daunted when they tell you they want fifty pages worth of materials as part of the application process might benefit perhaps. And their kid deserves supported living as much as Judith deserves it, so I would love to do something that would just help people to get through the process. So that's one future plan in my mind.

I want to see the launch of this Community Partnership Agreement Foundation, so I'm going to stay involved with that a little while longer, try and help get that going. And probably stay with USA a little while longer, too.

I'm getting back into the technology aspect of Jude's life, her specific technology needs, which I haven't had a lot of time for. I've been busy attending to the world of technology instead of my kid's technology, so we're working on some really interesting stuff together. I'm trying to be a mentor to her and introduce her and help her with some training. And god, she's so talented in this area! She has more intrinsic skills with computers than I ever did. She loves this stuff and can't get enough of it and so I'm trying to keep up with her in that and learn some new things at the same time.

I'm spending a lot more time sort of being a parent to both of my grown kids in some ways--visiting Michelle as I can. Steve and I are doing a little travel together and just really trying to have a more calm life. I'm not quite there yet, but that's my aspiration.

There's a change in climate in California with the new administration. One thing that I'm wondering is whether the climate is going to grow for some kind of legislation to fund

assistive technology by some sort of small surcharging everybody's something or another in the future. I have some ideas about how to promote system change to make technology more available to people. So there are a few of those things that are in my mind as well.

Jacobson: Would you like to stop, or do you want to go onto other stuff?

Brand: What do we have to do still?

Jacobson: Just any other things you might want to add.

Brand: I feel a little bit wiped out by now. On the other hand, I feel like we just have a few moments really left, and it would be good to try and charge forward. Did you just want to hear a few miscellaneous thoughts that I had?

Jacobson: Yes. Let me turn the tape over.

Brand: Okay.

##

Jacobson: Jackie, I've been looking at my notes and now I realize that there's a little more we have to talk about on tape than I anticipated, so why don't you just finish your thoughts for now?

Brand: Okay. [tape interruption]

Well, I'm kind of stepping back outside of the trees and looking at the forest a little bit at the end of all of this and trying to think about maybe what some of the big pieces have been for me. And I'll just say just a few things about that. It was an extraordinary thing for me to grow up and parent in this community because the opportunities here were so unique and so different from most other places in the world. It has been amazing to watch the evolution of a movement and see the early days of all of that.

And also, it was difficult to do that as a parent in a community where there wasn't a good integration of parents into the movement; parents were often excluded. I think it might have been necessary in defining the movement, but it prevented the connection of kids with mentors and people with disabilities. That wasn't naturally built in; you had to fight to make that happen. And that's unfortunate. Hopefully things will evolve to a point or are evolving to a point where parents

and kids--children are a part of a broader movement, and then that movement is part of a larger movement in the world as well.

And that goes back to some of my USA thoughts. To me, I'm always trying to figure out how that coalition is bigger. I think there are times when you narrow in to create an identity and then broaden out to create impact, and in effect, power. And that's where I hope that we're moving.

VII REFLECTIONS

[Interview 6: March 7, 1999] ##

Need for Parent Integration in Independent Living Movement

Jacobson: Jackie, I wonder if you could give us your thoughts on your experience in general concerning parenting a disabled child.

Brand: Well, that's an open-ended question. Sure. Stop me if I start saying things that I've already said sixteen tapes back.

Jacobson: If I remember.

Brand: Well, [laughs] that is a problem--it will sound new all over again, right? [laughter] Well, I have just a few points to make, but one is--and I'm sure I've alluded to this everywhere the months that we've been talking together--but the challenge of very often being a parent of a kid with a disability without having had direct experience with disability oneself. That creates an enormous learning curve on top of the enormous learning curve about learning about parenting in general. I wish there were more resources which involved families having opportunities to connect more integrally with the disabled movement from a very early point. It seems to me that that was one of the very biggest problems, that one could really not easily get connected unless one had the luck of living in a place like I did.

I had a lot of good luck in this, but I think I was unusual. I lived in a place where there was a very active movement and that was extremely important to me and, I think, important to my daughter, because not only did I get exposed, she got exposed. And we grew up with a very different perspective. Somebody might otherwise grow up with feeling isolated and unusual in a community where there are few people

with disabilities and very little presence in the community and in the social fabric.

What I've seen a lot of is parent movement and then the disability-focused movement. What I haven't seen is the movement that integrates family members into the disabled community as a whole.

Jacobson: Do you think that is happening at all? Do you have any idea how it could happen?

Brand: What I don't see is much focus of parents and families into the independent living movement and philosophy. It's more about a parent empowerment movement. And that's probably important, as well. There's probably a process, but I think that kids with disabilities would grow up with stronger resources and a fuller sense of identity and esteem and possibilities of their future if much, much earlier on they and their families were a part of the independent living movement. I don't really see that happening much.

I feel that in some ways it's been a real uphill battle for me to connect in that way. I think I probably understand that is part of the independent living movement itself. It involves separation from family to create one's own adulthood and reality and future, and so on. That's a natural and normal process that everybody goes through and needs to go through. And so there's a point where there appears to be kind of a conflict of interest, but I think when family members are pretty much excluded from that whole process it really does the next generation harm.

School Environment Liberation

Jacobson: One of the things I remember you saying to me here--or it was in a phone conversation--is that now that Judith is out of school and the special ed system, you felt that she and you were a lot more liberated. Can I hear you talk about that?

Brand: Well, I do feel that way. I totally do feel that way, and yet I also think that it's a minority experience. I don't think that experience is fully reflective of how people experience the immediate post-school environment. I don't know.

Jacobson: What do you mean by that?

Brand: What do I mean by that?

Jacobson: Yes.

Brand: Well, I guess I'm saying that Judith's experience of feeling liberated from special ed and from schools and my feeling along with her of feeling the liberation may not be the way most people--most families and kids--feel. I don't know. I'm not sure.

I do feel that there are tremendous limits on what the options are for kids with significant disabilities going through the schools--the public schools. Whether they're in special ed environments segregated from the rest of the school population, or in mainstreamed environments, they each have their side of the problems, in that it's very difficult to put together a balanced life that involves good strong academic support, good strong socialization experiences, and opportunities to explore whatever your interests are as opposed to those classes being in inaccessible locations and all the other complications about how the teacher feels about having you in their class and so on. Once you get away from all those limits, the world on some level, though a challenge, becomes more interesting. It is so amazingly liberating.

When you stop having to go through the special ed filter about everything and you just are looking at life and your interests, everything is so different, so utterly different. And what I suspect is that a special ed kind of childhood really sets in place this sense that there are a few special opportunities in life for you and that there's kind of a bureaucracy that surrounds everything in your whole life that will help to define and monitor and limit you. It's just so different from growing up not in that special ed world.

So I think that though there have been periods when Judith has had very good support for specific interventions that she's needed--and there have been times like that, the price to pay was enormous. And if it was enormous for her who has relatively significant and multiple disabilities, then it seems to me that the price is enormous for most other kids who have fewer needs for the specialized intervention. They just might be in a specialized environment because the school doesn't think they know what to do about the person.

The environment isn't established for them because they particularly need anything different. It always seemed very strange to me how you could say, "Oh, spina bifida. That classroom," as if a disability had anything to do with the

academic options and opportunities. It always seemed the strangest thing in the world to me to think that.

There are situations where I do understand: a kid with blindness learning Braille, that I understand; a kid with deafness learning sign language, that I understand, too. There are special needs that people have, particular specialized skills that need to be developed, but in general, those skills need to be developed on top of the same skills that everyone else needs, not in place of those skills. So the whole special ed environment strikes me as a mistake in concept, creating this parallel track as an alternative to education.

Jacobson: Now, where did you think that your experience or your view of being liberated is different than other parents with kids who are disabled?

Brand: Well, the reason I think that is from looking around at adults with disabilities after school. So many of them are doing so little with their lives, and so many of whose families feel discouraged and depressed about being outside of any system that would address their adult kids' needs.

It isn't an intrinsic value that everybody shares the same way. In fact, there are cultural experiences that very much diverge from that. In my relationship with the Latino community, my father being from Mexico, I am closer to seeing that experience. Typically I would say that in the Latino community, independence is not a strong value, especially for people with disabilities; it's more about family and taking care of our own and extended family stepping in and not about a person growing up and moving out.

So having as I did, more than Judith in the beginning, a very strong appreciation of the value of her independence and her quality of life on her own, that drove a lot of our thinking. On top of that you've got to look around for help or support for your kid to move in a direction she wants to go in, whether there appears to be a paved road or not. And that's another thing that's kind of scary, and you don't get a lot of support in doing that. What you'll hear from the professionals around is, "No, we don't do it that way," or, "That won't work," or, "That's not what you should do," and, "We know better." You, again, have to have a very strong kind of internal system and a belief in your own ability to maneuver through systems--or in spite of systems--and to figure out how to detour resources that were designed to go in one direction, to lasso them from one direction and put them in the direction your kid wants to go or to help make that happen.

In the case of Judith, it was absolutely necessary because she has a lot of needs that are expensive and there'd be no way she could have the life that she has if we couldn't figure out how to work with the regional center system, with the Department of Rehabilitation, and with the health system to figure out how to use their resources in the direction she wants rather than in the direction they typically do.

Then the last thing is having a sense as a parent of your kid, not through the eyes of professionals who tend to have more limited views, but by really knowing your child--her dreams and hopes and fears. You have to have a certain level of--I don't know if it's self-assuredness, or just stamina. I don't know what the combination of things are, but there is a combination of things that would allow you to strike out in a different way without a roadmap to follow.

I don't think most people have the resources to go there. Certainly a lot of people do, but I don't think most people do. Most people are going to be persuaded that somebody else probably knows better than they do, that somebody else is the "expert", and that there is something called expertise that somehow applies to somebody with a disability.

And for me, I grew up in Berkeley with the independent living movement. I had a chance to learn a lot and my experiences were very much formed by that experience. My values were formed by those experiences. I just consider myself amazingly lucky in that respect. My life is certainly enriched by it. I feel like I have a much broader view of life, but most important, I feel as though it gave me the ability to both think for myself and encourage my kids to think for themselves, and to have their own visions and to figure out how to problem-solve. I can not separate that from the role of technology in all of this.

That's the other big thing that I want to reflect on, because today, as we sit here, there's still no system for people to get technology in their lives. What the technology could potentially do to support people to do what they want in their life and what the technology currently does do for most people is just worlds apart.

The Gap Between Technology and Need

Jacobson: Now, what is it that is so difficult?

Brand: Well, there are a number of reasons. One is it's a pretty new area. Nobody really has ownership of it, nobody really is responsible for--if I look at the whole broad category of assistive technology, there's no obvious place where people would go to get assistive technology. If you think of assistive technology in the broadest terms, meaning whatever products and tools people would use to increase their independence, their functionality, their ability to do things, it would include standard products that just work well to wheelchairs to computers to velcro to switches to just a zillion things. It's so, so broad it's very hard to figure out where it goes or how people can get access to it. There's not an easy one-stop shop approach, and it's constantly changing because technology is changing.

It's great news, but it also makes it very difficult to find products. As long as these products are seen as having a very small niche market, which is the way the public misperceives technology--as having very little market--then there's not enough development, there aren't enough products made, so products are expensive and people can't afford them. And yet the research shows that the vast majority of technology that people get, they get because they pull the money out of their own pockets, not because medical insurance covers it or any insurance or schools or anything else. And stuff is expensive. It's medicalized and so it's therefore expensive.

Jacobson: You'd think that that in this day and age you could go to the Department of Rehab and say I need some adaptations or what is available to help me type faster--something like that and they would have access to that kind of information. Why isn't it there?

Brand: You would think wrong if you'd think that. [laughs] Well, you'd also think that the doors wouldn't close for people becoming clients of Rehab, but you know, they run out of money. They stop taking people period, so never mind providing tools. Also, again, there's no system built in which says that a Rehab counselor will have expertise in assistive technology--job-related assistive technology.

Jacobson: Okay, what about rehab centers like Stanford or the Institute of Rehab that's in New York?

Brand: What about Rehab sending people to those places?

Jacobson: Yes, or what about the centers like those, who are supposed to know about the newest technology?

Brand: What you'll find is that for the centers that do exist, they're few and far between, they're understaffed, and undersupported because there isn't yet a sense of their importance. Most of these centers work on grants, on soft money, and again, there's not a systemically built-in resource that says, "Wait a minute, a person with a disability is very likely to need a wide range of different technologies over the course of their life from childhood through old age--as we all are likely to need technology over the course of our lives for different reasons." It's just not built into the system yet.

Therefore, the training programs for the professionals that go into various fields like education or rehab include very minimal exposure, if any, to assistive technology. There are few opportunities for internships where people get hands-on training. And people are afraid to embrace it because it looks like a black hole of expenses.

Schools, for example. . One of the things we learned at the Center for Accessible Technology that was so shocking is parents don't learn about a technology center like that even though teachers know about these centers. They're afraid if parents go to these centers, they will learn about technology that would benefit their kids and then ask for that technology, so they are directed not to tell families about these resources. And again, it's that feeling that all of these systems operate with such underfunding that they're constantly in a position of trying to be a gatekeeper and it's a very discouraging process. So instead of thinking how technology's literally going to change the way you think about your life and the jobs you might hold, instead of saying that, they say, "If they see this screen reader they're going to want it and it's so expensive and now we need a bigger computer with more RAM," and this and that. We just have not yet internalized as a society the cost to all of us of not developing a system of access to assistive technology. We have decided it's easier to put our head in the sand.

That's changing slowly. I mean, we do have legislation, we do have IDEA, which requires that we consider technology. It's now in the law, and there are slow changes taking place, but it hasn't translated yet into meaningful access for a majority of the people who need it, who truly need it. On the other side, the straight technology side, because of the work that I've done in my life, I have access to a lot of the technology resources for Judith, but it has been very slow to get the right technology for her even knowing the latest stuff that's available because in fact the field is still pretty new and clunky. It still hasn't evolved where it needs to be to really

offer her the level of technology that she needs. I mean, she has technology that dramatically changes her life. I don't want to suggest she doesn't. But it's taken years to get that and there's still a long way to go. We're dealing with products that don't quite work together, that are you know, complicated. Built into her technology is the requirement for always repairing or modifying it.

Jacobson: So do you have any solutions? What do you think would--

Brand: Well, there are multiple solutions. I mean, there are just a lot of things that need to take place. Just to start out with, we need to build in a low or no interest loan fund that people can borrow money for technology and pay it back slowly with no interest so we can loosen up people's access to tools. We need to build in training. We can't let anybody become a doctor without being introduced to assistive technology. We can't let anybody become an OT or a speech therapist or a teacher without being introduced to assistive technology. We need to build it in on so many different levels. We need to offer training, broad training. We need to strengthen legislation. We need to offer incentives for employers to purchase assistive technologies, tax credits, and tax incentives. We need to build in a bias toward instead of a bias away from assistive technology.

And that's going to take work, but it's doable. I think once we get to that point where people taste the liberation of being able to make your own phone calls instead of waiting for somebody to come to the house that you hire to make a phone call for you, and people are able to get online and order something instead of waiting to be able to get a paratransit system to drop them off at the bookstore, or whatever; when people begin to see the benefits, people won't be willing to give it up. They will understand its power.

And that's the other piece that I think is still broadly needed, just a public awareness campaign so that people understand what assistive technology is all about in the first place. There isn't enough demand for it yet because people don't know what it can achieve. And people have just bought into low expectations for their own lives. So there's a lot of things that need to happen, but I see that it's a very doable thing and we're certainly on the road.

Value of Social Ritual ##

Brand: This is probably something we've talked some about, too, but the lack of support after school--and I don't mean support as in programs. I mean social, societal support--I just think there's a huge lack of ritual and process for kids leading into adulthood. For a certain minority of kids becoming adults, who are going a very acceptable, highly validated route--academia and college and all of that--there's a certain comfort in a pathway just continuing, but for most of the rest, with and without disabilities, there isn't an easy route. There isn't a social system that supports that process of growing up and identifying strengths and addressing needs and all of that. And I think that's part of why families are scared to see the end of the school period and keep their now young adult kids in school until the last moment, which is age twenty-two, if you've got an IEP--fearing what lies beyond.

And while, again, I felt that leaving school was liberating for Judith, it was also scary. A lot of people feel very frightened about that because there isn't any kind of a mentoring or even a ritual. Do you remember, there used to be something called being sweet sixteen? There ought to be something connected to being twenty-two or eighteen. There ought to be something that recognizes that huge big step you're taking. It's like the equivalent to bar mitzvah in some way, only that comes younger, that just says, "Now I have new responsibilities, and I have new opportunities, and there are lots of things to be thinking about," and trying to think about different opportunities. I think kids and young adults with disabilities would benefit a great deal from it, but many nondisabled kids would benefit from that as well.

Jacobson: Say that again. You're speaking so fast I can't understand if you think kids without disabilities would benefit way more than--

Brand: Oh, no, no, equally.

Jacobson: Okay.

Brand: What I'm saying is, it isn't strictly a disability-related issue. It used to be you grew up and you did whatever your father did if you were male; if you were female you'd do whatever your mother did. And there weren't any particular options: they'd teach you this trade or craft. She would teach you how to take care of the house and raise children. I mean, it was very prescribed. And we moved away from that into,

well, there's a whole system if you're going away to school, but we haven't moved into there's a whole world out there. I'm just saying it isn't really strictly disability-related, but kids with and without disabilities would really benefit from something that followed school at a certain point in one's life that acknowledged that process of becoming an adult and thinking about one's values as an adult, one's desires, and one's goals.

We just think, are you going to college or not. We think, did you get a job or not. And you know, kids go to college or go to work at McDonalds as if those were the only options in one's life. Certainly for kids with disabilities growing up, the McDonalds option is basically what we offer if you're not extremely bright and make an uphill battle in college. You might go academia, but there are few options in between. I think it's also true to a large degree for nondisabled kids, so anyways, that's another point that I wanted to make.

Jacobson: Is there anything you might have done differently?

Brand: I wished Jude had had a different kind of school experience than she ended up having. But I don't know if anybody has it yet, so I can't think what I would have done. It was more about just dealing. I wish the environment wasn't what it was. I guess I don't think I would have done things differently, but I don't tend to look back in that direction so much. In other words, if there are things I'd do differently, I try and just do them differently, you know, because there's usually plenty of time to do that.

We made a lot of changes over the years. We moved several times for different reasons. I think what I've learned is that one should always expect one will make mistakes, but no mistake is fatal. And one should feel comfortable enough to try different stuff and take a different route when the route you're on seems to be counter-productive.

In that process, in that journey itself, you try to give yourself enough slack to be as imperfect as you're going to end up being, but to give it your best shot. And then to be ready to evaluate, look critically at things as they turn out and be willing to say, well, that was not the way to go, let's do something different. And also to always be guided by paying good attention to your kids. And when you're talking about parenting, your kids will give you the cues if your eyes and ears are ready to process those cues. So that's I think that's more what it is, as opposed to making some long-term decision

and then looking back and saying, "I wish I hadn't spent ten years doing this or doing that."

Wisdom from Experience

Jacobson: What do you say to other parents who have disabled kids?

Brand: Well, I don't know that I have any particular wisdom, but I think I often talk with people who are discouraged, especially with the schools, and also depleted. I run into people who get depleted.

Jacobson: They need energy.

Brand: Yes, they're tired and depressed and discouraged about solving an issue. And it's usually not their kid's problem; it's usually the people their kids have to interact with. That's usually where it happens.

And one of the pieces of advice I give very often--it took me a long time to learn--is that sometimes you don't win a particular war, you pass on it, or you save your strength, or you just give up sometimes because you've just got to rejuvenate yourself. One single decision doesn't tend to be fatal.

And having seen myself get depressed and discouraged and overwhelmed with stuff that needed to happen, I began to realize if I'd take a little break I'd get my energy back and go back at it, because you do. But sometimes it's hard to realize that you will, this feeling that somehow you've got to be at war at every moment, vigilant on behalf of your kid. And it just makes you crazy. You just can't go twenty-four/seven like that. And survive.

You need to begin to pace yourself and know when to go and when you stop. And sometimes it's the issue and sometimes it's how you're feeling, and both of those are legitimate reasons.

The other advice I give now is for people to realize that there is a lot ahead beyond school which really requires a lot of creative thinking. It's very exciting but it's going to take a lot of time and energy, so don't go burning yourself out over the third grade reading teacher. You have to put the issues into a broader perspective. You have to think more long-term and look at your own resources and your kid's

resources for surviving things that are less than perfect. Kids are very resilient and they learn things in that situation, as well.

And then of course I'm passionate about exploring technology with your kids, and seeing that potential when people talk in terms of their kid's limits. I like to invite people to question whether those limits are being pushed onto kids appropriately or whether they shouldn't be put aside. I mean, it used to be that people would say you shouldn't have unrealistic expectations for your kid, but my mantra when Jude was younger was that it's absolutely critical that every parent have unrealistic expectations for all their children. I think that's part of the experience of parenting.

Jacobson: That's good to remember!

Brand: Absolutely. I resent the people in the world who said--and I can't tell you how many people put to that me--"You're not realistic. You don't have realistic expectations." Nobody would ever say that to me about Michelle. If I expected her to grow up and be president of the United States, or queen of England, they would have thought, "Oh, isn't that nice." You know, the parent who has great hopes for her kid. But if I would have said, "Well, I think that"--you know, anything about Judith, they would ask, "Well, are you being realistic?" And so I think realism sucks, basically, and is just a very limiting factor.

And there's a certain point when everybody has to deal with their own expectations and their own realities--realities will hit you whoever you are, that's the nature of life--but to create these low expectations, or not to have wildly high expectations and encourage your kid to dream and have every expectation for himself or herself possible, to me, that's what parenting is all about.

Jacobson: So do you foresee a lot happening in the area of technology over the next twenty-five years? Is there anything you would like to comment on?

Brand: About technology? Well, one thing I know for absolutely certain is we can't even comprehend what's yet possible. We have barely touched the tip of the surface, and the limits on the evolution of technology will be in whose hands the decisions are, and how creative and how broadly people can think about what technology can do to support peoples growth and development and change, so I see it as a tremendously exciting force into the future.

I've said for years and years, and I believe it, it really redefines what it means to have a disability. It redefines this notion of ceilings on what people can do, one's functional skills, whether one is labeled with a disability or not, or as far as anybody could go. It's absurd right now: it's like saying you can't possibly be flying in the air because you don't have wings, when there are airplanes. So for people with disabilities, that's just as true, and sometimes even more thrillingly true.

That's why to me it's very important that there are people who are thinking and pushing new technology and have clarity about what are the tools that would provide new skills and would be liberating. What are the next things that we're not thinking about yet that we ought to be thinking about? And get to that. And so the next twenty-five years are going to be unbelievable, I think.

Jacobson: Okay. Jackie, is there anything we didn't get to? [laughter]
Jackie, we're done, unless you--

Brand: Well, you have everything but my shoe size!

Jacobson: I don't think we need to verify that.

Brand: No, I'm keeping that a secret. [laughter] No, I appreciate this--it's been fun to do, I've enjoyed it. It's been exhausting, too, and I know we're not quite done yet because we'll have to look through the transcripts and so on, but it's been an interesting journey for me to look back. I appreciate and thank you for joining me on that journey.

Jacobson: You're welcome.

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Disability Rights and Independent Living Movement Oral History Series

BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY
VOLUME V

Doreen Pam Steneberg

PARENT ADVOCATE FOR EDUCATIONAL RIGHTS FOR CHILDREN WITH DISABILITIES

An Interview Conducted by
Julie Drucker
in 1999



Pam Steneberg with daughters Susan (1 year old) and Jennifer (5 years old), 1971.

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INTERVIEW HISTORY--Doreen Pam Steneberg

A lifelong advocate for people with disabilities, Doreen Pam Steneberg is a nationally recognized spokesperson for the rights of children with disabilities, and herself the parent of a daughter with a disability. Ms. Steneberg was born in England where she studied to be a nurse. She immigrated to the United States in 1963, married in 1964 and practiced nursing until the birth of her second child, who has developmental disabilities and cystic fibrosis. Through preschool activities on behalf of her daughter, Pam met other parents who were frustrated at the lack of both services and educational opportunities for children with disabilities. At the time, such children were excluded entirely from public schools, receiving limited education in segregated facilities. As her daughter reached elementary school age, Pam began devoting most of her time to advocating for education policy reform. She joined the parent advocacy unit of the Berkeley Center for Independent Living's Disability Law Resource Center in the late 1970s and later the staff of the Disability Rights Education and Defense Fund where she worked until retirement.

As a parent advocate, Ms. Steneberg has trained thousands of other parents about their children's educational rights, served on scores of community boards, and provided technical assistance and guidance to countless parents throughout the country who wanted to challenge the exclusion of their children from public schools. In 2000 she was awarded the first Ilse Heumann lifetime achievement award by the National Parent Network on Disabilities. The award was named for Judith Heumann's mother. Judith Heumann welcomed Pam and other parents to be part of the independent living movement when they approached the Berkeley Center for Independent Living in the late 1970s. Though semi-retired, Ms. Steneberg continues to devote herself to working for the rights of all children with disabilities. Her daughter Susan is living independently with a roommate.

This interview was donated to the DPIM oral history project by Julie Drucker who interviewed Ms. Steneberg for an oral history class assignment through UC Extension. Three interviews were completed between January 26, 1999, and March 19, 1999. The tapes were transcribed by the Regional Oral History Office. Editing and final proofing was done by Sharon Bonney from the Regional Oral History Office. Ms. Drucker and Ms. Steneberg reviewed the transcript, clarified questions and provided additional information where necessary. Ms. Bonney prepared the interview history with the help of Mary Lou Breslin, another member of the DPIM team. Copies of interview tapes are available for listening and research at the Bancroft Library.

Sharon Bonney, Editor

March 27, 2000
Regional Oral History Office
The Bancroft Library, University of California, Berkeley

Regional Oral History Office
Room 486 The Bancroft Library

University of California
Berkeley, California 94720

BIOGRAPHICAL INFORMATION

(Please write clearly. Use black ink.)

Your full name DOREEN PAMELA-BATES STENEBERG
 Date of birth 05/15/36 Birthplace Gantham Lincolnshire
 Father's full name Kenneth Arthur Bates
 Occupation Air force Officer Birthplace Kings Lynn, Norfolk
 Mother's full name Minnie ~~Donna~~ Surle-Davis England
 Occupation Nurse Birthplace Liverpool, England
 Your spouse George S. Steneberg
 Occupation electrical engineer Birthplace Berkeley, CA
 Your children Susan ^{Nicola} Steneberg
 (eldest) Jennifer Lesley Steneberg
 Where did you grow up? England
 Present community Berkeley
 Education R.N. (Registered Nurse)
 Occupation(s) Nursing, teaching and advocacy
 Areas of expertise Nursing, Disability training, ^{child} rearing
Homekeeper, administration, fundraising,
Development, politics, Parent advocacy, ^{policy} development
 Other interests or activities gardening, calligraphy,
drawing, volunteering

Organizations in which you are active DR E D F (Disability Rights
Education + Defense Fund), ~~DR E D F~~ (Parent and
advocates for Special Education), A SE, steering committee
for CIS (California for Inclusive Schools)
Health Task Force for Long Term Care for Central

Law, Public Policy, Training and Technical Assistance

DOREEN P. STENEBERG
9 Pomona Avenue
El Cerrito, CA 94530
(510) 525-9125

EDUCATION

1963 Contra Costa Jr. College, San Pablo, Calif.;
Psychiatric nursing

1959-1960 Lewisham Hospital, London, England;
Certified operating room nurse

1958-1959 St. Mary's Hospital, Portsmouth, England;
Certified midwife

1954-1958 Hastings School of Nursing, Sussex, England;
State registered nurse

EMPLOYMENT

Present Parent Advocate - Disability Rights Education
and Defense Fund, Inc. (DREDF), Berkeley,
Calif.

Private Scrub/Staff Nurse - Dr. Howard Lee

1987-1988 Parent Trainer - Team of Advocates for
Special Kids (TASK), Berkeley, Calif.

1981-1987 Surgical Staff Nurse - Surgical Staff, Inc.,
Sunnyvale, Calif.

1983-1985 Parent Consultant to DREDF - Parent training
Project funded by the U.S. Department of
Education

1963-1982 Operating Room Staff Nurse - Brookside
Hospital, San Pablo, Calif.

DISABILITY EXPERIENCE AND TRAINING

1985-Present Parent Advocate - Disability Rights and
Defense Fund, Inc., Berkeley, Calif.

 Develop IEP meetings and provide technical
assistance for parents of disabled children

Present Advocate Trainer - Americans with
Disabilities Act (ADA)

Doreen P. Steneberg
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1984-1990	<u>Training</u> - Regional Center of the East Bay
1989-1990	<u>Epilepsy Training</u> - Memphis, Washington, D.C.
1982	<u>Advanced Advocate Trainee</u> - Section 504, Advanced Training, San Francisco, Calif.
1979-1981	<u>Parent Advocate</u> - Disability Law Resource Center, Berkeley, Calif.
1981-1983	<u>President</u> - Parents and Advocates for Special Education (PASE)
1977-1981	<u>President and Advocate for Cameron Parent Group</u> - El Cerrito, Calif.
	Coordinated compliance with school districts in special education issues
1980	<u>Advocate Trainee</u> - Section 504 Training, San Francisco, Calif.
	<u>Parent Technical Trainee</u> - Under the Master Plan for Special Education in California
1973-1977	<u>Advocate and Treasurer of Hilltop Parent Group</u> - El Cerrito, Calif.
	Developed and implemented programs for creating community awareness and involvement; fund raising

CURRENT ORGANIZATIONS

Vice-President at Secretary <i>p.a.</i>	National Parent Network on Disabilities (NPND)
Board Member	Developmental Disabilities Council of Contra Costa County, Calif.
Board Member	Area Board V - Nominated by Developmental Disabilities Council and Board of Supervisors of Contra Costa County
Board Member/ Past	Area Board V - Bay Area Counties of Calif. Regional Center of the East Bay
Member	Parents and Advocates for Special Education (PASE) / (PTA)

Doreen P. Steneberg
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President	Crippled Children's Society, Inc. of Contra Costa County, Calif. (CCS)
Member	Association of Operating Room Nurses
Member	California Nurses Association
Member	American Nurses Association
Member	Association for Retarded Citizens
Member	Parent Teachers Association
Member	Epilepsy Foundation of America

PDS:ams

INTERVIEW WITH DOREEN PAM STENEBERG

I FAMILY LIFE IN ENGLAND AND THE UNITED STATES; PARENTAL
ADVOCACY MOVEMENT

[Interview 1: January 26, 1999] ##¹

Early Life in England with Undiagnosed Cystic Fibrosis, 1936-
1963

Drucker: I am here with Pam Steneberg on Tuesday, January 26th, 1999, at the start of Pam's oral history. Pam, can you say your date of birth and where you were born?

Steneberg: My date of birth is May the 15th, 1936, and I was born in Grantham, which is in Lincolnshire, in the center of England.

Drucker: I would like to start this interview by talking about your childhood or your adolescence and your own illness and how you first came to experience disability for yourself. Can you tell me a little bit about yourself and when your disability began.

Steneberg: Well, I was born in England, and it was during the time of the beginning of the war and also all of the war, when I say war, I mean World War II, so it tells you that I am rather ancient. I want you to understand that I don't think I was really aware that I was disabled for a long time. As a child, I was trotted around various TB [tuberculosis] clinics by my mother, who actually was a nurse herself. She, I think, had a sixth sense or something like that, that she knew something was wrong with me, but she didn't know what.

She took me to these clinics because those were the clinics which were available during that period. A lot of people during that wartime period did have or developed

¹ ## This symbol indicates that a tape or tape segment has begun or ended. A guide to the tapes follows the transcript.

tuberculosis, which up until that time had not been that common.

However, during the time that I was going around these various clinics, I was always told that I did not have TB, and that they didn't know what I had. So a kind of regime was thrown together which was, at that time, more hit and miss than not. I was known at that time as a sickly child, but I was never really made aware that I was disabled in any way.

I attended school, and I did all the "normal" things that other teenagers did or children did in school--teenagers also, for that matter. I was exposed to just life in rural England because we were evacuated during the wartime and taken from the cities and put, sometimes, in other people's homes, in small villages and towns other than near the big cities.

Nutrition was of the utmost value at that time, but it wasn't very forthcoming because there was rationing. We were very fortunate, however, in our life or my life, I should say, because I stayed with a woman who was very enterprising and who we grew to know very well and loved dearly. She had her own vegetable garden, and she also raised pigs. So we had a great old time, like on a farm. I suppose we ate quite well, considering all things.

There were a lot of things we were deficient in, obviously, because of the wartime and, as I said, rationing was of the premium. I mean, we got two ounces of meat a week, if we were lucky. I can remember going, standing in line to get maybe one orange if there was a shipment or a box of oranges brought into the village.

So that will tell you kind of briefly how we were deprived of a lot of things during the wartime years. But we managed to survive somehow, all of us, and I suppose that's why my survival rate is kind of pretty high. We made do and pulled through and somehow survived.

Drucker: When did you feel--if it was later on--that your illness made it difficult to continue a normal life? Is that when you were in nursing school? Did your illness escalate later on after you were twenty or twenty-one?

Steneberg: Well, I suppose it was always escalating, but I didn't really have much handle on that. I just felt, well, this was my life and this is what one should expect. I mean, I didn't really dwell on it or think about it that much. I did know that I got infections rather easily. I had a hard time and was

discriminated against very much so in the early days of trying to obtain employment, mainly because people didn't want to take the risk of having me be part of whatever they were involved in.

But I did want to be a nurse, and I had a very strong desire to be a nurse. I applied to several training schools, and I did manage eventually to get into one, I think mainly because the person who was matron, as we called her--that was the chief head nurse or whatever you want to--who was in charge of the hospital, the nursing staff; decided that she would take a chance, and took me on in training school. But she told me that if I didn't, couldn't make it, I would have to leave. It wasn't a matter of either/or. It was a matter of "If you can't make it, then you won't be able to stay."

I was very determined to stay, of course, and so I worked very hard to do that. I not only worked hard, I kind of studied and did all the other requirements. It was a very taxing time because in those days we worked a six-day week. We had one day off a week. We worked long hours, and also I think that's where I learned to incorporate my life into my work.

So there are many reasons that I think contributed to my survival, as we say. Also, I had what I consider small successes. Other people perhaps didn't think that I was as good a nurse as I could be, but I felt very comfortable and I felt that I did a good job. A lot of people admired me, and several of my friends in training, who were very sincere, assisted me in many ways to get through my training period, because it was gruesome and it was difficult.

It took me four years to do my training, when it should have only taken me three. I was sick during that time two or three times. I had a lung abscess one time, which I managed to get over; and I had my appendix out as an emergency; and various other times, I was off sick over the lung abscess for about six months. Standing on my head and doing all kinds of things.

Just to cut a long story short, my childhood was--far from not being eventful--it was very odious at times, and also my training period when I was a nurse was very strenuous. But I enjoyed it. I really did. I mean, I have enjoyed my time in nursing. Of course, there were times when I didn't like it, along with everybody else. But I didn't feel that I was any different from anybody else.

That's about all I can say about it at this point. Then, I think, I really realized that I had this disability. I don't think I called it that. I had this illness, and it would be with me forever, and I'd just have to live through it. It wasn't till I came to this country and looked at myself in a different way that I realized I was a disabled person. So that's all I can say.

Drucker: How did your family treat you all those years when your mother was taking you to doctors? Did they treat you differently because you were ill?

Steneberg: You know, on the whole, I don't think so. My mother probably did. She probably spoiled me more than any other. But the rest of the family just thought, "This is the way Pam is." I mean, it wasn't really an exercise in trying to decipher or determine whether I was normal or not--because I did take care of most of the family, the kids--mainly because my father was not around during the wartime.

He was in the air force, and he was already in the air force before the war broke out. When war broke out, he was in Iraq. We didn't see him till about three years after the war started; then he was able to get home. So really I was brought up, as far as I can remember, in awe of my father and was rather frightened of him, actually, when I met him. I didn't really want too much to do with him, mainly because he was a stranger to me. So it was kind of difficult in the beginning years.

He was very resentful. He also was mentally ill. I don't think it was all his fault. He abused me verbally a lot, and even two or three times attacked me because he was angry, mainly. Even my brother says to this day, "Our father abused you." I've never really asked him what he meant by that, but I think it was mostly verbal--shouting--abuse. But I can remember him really hitting me and throwing things at me and that kind of thing. It was all resentfulness. It was kind of like, "Oh, I'll always have to take care of you. You're nothing but a nuisance. You're a pain, and I'll always take care of you," which was very hurtful and very trying.

But I was determined that I would make it on my own. I said, "I'm leaving now," and more or less walked out and went to the nursing school. That's how I became a nurse. I didn't know whether I'd be accepted or not, but I didn't see any reason why I wouldn't. Basically, that's how I got started.

Drucker: So will and determination have played a large part in your life.

Steneberg: That's correct.

Move to the United States, and Marriage, 1963-1964

Drucker: So you came to this country and got married and settled down here. Did your attitude start changing about disability even before you got involved with the movement, or was it around that time? Was there anything else that influenced you? We're talking of the sixties as a period of history.

Steneberg: Well, in the early sixties, when I came to this country, I arrived here in '63, I felt that I had this chronic disease which I needed to take care of in the sense that I had to be careful about what I chose to do and how often, and not to overdo things and all that. As I said, I didn't dwell too much on it. But I came here because I was a nurse, and I decided that if I wanted to see the world--which I did, very much so, at that point--I had a plan which was basically to come to this country for a year, or California for a year. That's what the contract was with the hospital that I was going to work at, and then I was going to go for a year to southern California and work. Well, it turned out that my friend went and did it--in Santa Monica Hospital--and worked there for a year. Then I had planned to go to Hawaii and work for a year and then go to Hong Kong and work for a year, if that was possible and we could find jobs.

Having plans to do that, we were going to find jobs before we left, which is what we managed to do to come here. So when we worked off our payback, which was the fare, and we got started, I didn't go any further because I met my husband. I was only here about five weeks when I met him. He asked me to marry him. I, in the beginning, laughed and said, "You won't like this," or "You'll regret it," et cetera. I kind of laughed and thought it was a big joke in the beginning.

But then gradually I decided that I really loved him and that I really wanted to be here and be part of his life and my life together; somehow I came to that conclusion and proceeded to marry up here in this church just up the street from where I'm living, and settled down, which I started to do.

My friend moved on and went down to Santa Monica, which was a very difficult parting because we had been friends for many years. We had decided to do this whole venture together, anyway. But after all the emotional passing back and forth and deciding that this is what I was going to do, right or wrong, I'm afraid that's what we did.

So anyway, that's what has brought me to this point, and since that time, of course, I've had two children, who are American citizens, and my husband also is an American citizen, born here, in Berkeley. In fact, they were all born in Berkeley, which is rather a coincidence, but that's how it is.

Drucker: Can you tell me, after Susan was born--

Steneberg: You mean Jennifer?

Drucker: Sorry, after Jennifer was born, what year was that?

Steneberg: Well, Jennifer was born in 1966 [chuckles]. I have to try and remember. Yes, '66. She was born July the 29th, 1966, two years after I had come to this country, two years later. She was born in Berkeley, as I mentioned before, at Alta Bates Hospital. My biggest fear, of course, at that stage in the game, was that she would not be normal, and I was pleased to find out in the beginning she was, physically. I think she probably still is, but we're not sure as this has transpired, as probably nobody realizes, into a family genetic disease, which is basically cystic fibrosis.

Whether I have cystic fibrosis or not is another story. It runs in the family, obviously, which we found out in latter years, we had no idea about in the beginning. So I only was concerned at that point that she was physically sound and okay, which she appeared to be, so that was fine.

It's only in latter years, since Susan was born--my second daughter--that we had investigative things done and genetic counseling and all that. So it's kind of a whole different game now than it was in the beginning. Things are looked at from a different perspective, of course.

It's difficult to determine what is considered to be detrimental and what isn't, because medical science has advanced so much during the last ten, fifteen years, even, that it's difficult to say exactly what one knew before, and what one didn't. The present-day knowledge is far vaster, and I probably wouldn't have done a lot of things. I probably wouldn't have had any children if I had known what I know now,

then. It's fine to say that, but it's not possible to go back in hindsight, and we'll have to live with whatever has transpired since.

It's difficult to record this and say how I feel about it, because obviously what I feel is in present, and I can feel very guilty about a lot of stuff that happened in the past. I'm trying to get over that, which is not helping me right now, to heal and to deal with the rest of my life, however long it is.

That's the story about that. But my daughter is a large woman, who has done very, very well. I'm very proud of her. She has carried an awful big load. She's always had two or three jobs and gone to school and done all of those things, and she's now in law school and shortly, in May, will have finished law school and be taking the bar, so I'm looking forward to that being accomplished, at least. She's very smart and very intelligent and deserves the best she can get in life. I think I can say I'm very proud of her.

Daughter Susan Born with Cystic Fibrosis, Mental Retardation, and Cerebral Palsy, 1970

Drucker: Can you tell me when Susan was born, a little bit about that, since that was your introduction in some ways to the disability community and probably was what prompted you to get started in the movement, I think.

Steneberg: Well, you're absolutely right about that. After Susan was born I wasn't told immediately that she had cystic fibrosis, I was just told that she wasn't doing that well. It was obvious. She was also mentally retarded, and she had cerebral palsy, and she couldn't sit up from the beginning, and all kinds of things. All things being considered, she has done extremely well.

She had a very precarious childhood, with a lot of determination, again, by myself to do right by her and to help her as much as I could, which was very hard work, I can tell you. And gradually dealing with my own thoughts about having to do less and less work at nursing and give more and more time to taking care of her and to meeting her needs. Not actually taking care of her as an individual, because she was in a lot

of services very rapidly. Sometimes I didn't think rapidly enough.

In all of that, I was determined to find out and give her the best quality of life that we could, so she was in a day treatment center and she was also in various schools which were in special education. During that period, I was introduced to the disability community because I was trying to obtain for her her rights under the law, which had just been developed and come out at that time.

Drucker: What year was that? Do you remember?

Steneberg: Well, it was started for Susan not too long after she was born. She was born in 1970. She was immediately placed, as I said, in this treatment center, which she went to daily. I went there a lot of the time and helped and volunteered.

Drucker: Even as a baby, as a toddler?

Steneberg: Yes, as a baby. She was, when she first went there, just over a year old. It was very hard to do that, but it was necessary, I felt. Pre-school-wise, and from one till one and a half to two, she went daily to the day program. I was introduced to other parents, and very quickly, being a nurturing type and also a nurse, I tried very quickly to help other folks deal with their children's problems, too. So we kind of came together in a way which developed into a very long-lasting peer group, in which we gave each other support, and we did various trainings or conferences for finding out what was the best treatment, and where to go, and all of the resources that were necessary to help our children.

Drucker: Was that how you first were introduced to DREDF [Disability Rights Education and Defense Fund]?

Steneberg: It wasn't DREDF in those days. It was started as a different entity under the Center for Independent Living, and it was called the Disability Law Resource Center [DLRC]. It was across the road from CIL [Center for Independent Living], in a building, but it was put together by them. When we first went there--because we felt our children did have rights, and we needed to find out what they were and learn about them--the director that we talked to first of all felt our cause was very just and felt that this was a beginning for her. Then the attorney we talked to also felt that this is where we should start, putting this new law [Education for All Handicapped Children Act, 1975] in place.

It happened to be Arlene Mayerson, and then we talked with Judy Landau, both of whom are now attorneys in disability law. We then talked with Judith Heumann, who was the director of this center, the Center for Independent Living. She was very adamant that we should be given service from them, which we did. We joined in with them and even though we didn't feel part in the beginning, because we felt that, I think, a lot of people resented our being there because we were parents.

At that time, they all didn't feel very good about their own parents, because they felt they had to work this out. They felt we were interfering in their world and that their parents didn't do right by them by shutting them away in little schools and hiding them away in their houses and not really letting them live normal lives and go to schools like everybody else.

Drucker: But you were fighting for your children to have a normal life, to be totally integrated.

Steneberg: Yes, that's exactly what we were fighting for. That's what we wanted because we believed in it. We didn't think our children should be treated any differently because they were disabled; they needed to be exposed to the world, just like everybody else.

Drucker: Was the day program Susan was in state run, or was it a private program?

Steneberg: Part of it was county run, part of it was money that came from the federal government, and part of the money came from the state government. I suppose it's a combination of all of those things, and grants as well, many grants through the years.

Integration of Children with Disabilities into Public Schools, 1975

Drucker: When Susan was about to start kindergarten, would she have been completely isolated, segregated into a class of special education children and not integrated at all?

Steneberg: That's correct. The center itself was not integrated. It was just all special children, children who needed--they felt, in that time and age--needed to be kept separate. They needed to be given intensive treatment, which is good, but that's not the only thing they need; they need socialization with normal people to make them whole people and whole beings. They needed

to be given the same opportunities. Civil rights are civil rights. To deny people, anybody, the opportunity to participate in society is not where we should be at, even if we are now. Lots of people still are. People need to understand that we have the right to go in the street and walk around with other people, and we have the right to do anything that everybody else is given the opportunity to do. We can't be denied those rights.

Drucker: Do you feel that the civil rights movement of the sixties and the women's movement influenced how you felt about integrating, or was it as a mother seeing that their child needs what everybody else's children need? Was it a combination of both of those?

Steneberg: It was a combination of all three of those things that you talked about. I have a big need to feel very much like everybody else, as I told you before, and I was always treated that way.

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Steneberg: I always felt that I should be--and I was, as I said--given the same opportunities as everybody else. I mean, I was probably treated a bit more special than somebody else, but I wasn't really. I went down and had treatment every so often, and did all kinds of other things which were not what everybody else was doing, but at least I did it because I had to or I was told to, made to do those things that children have to abide by the rules of the parents.

That's basically what it's about. I believe very strongly in civil rights for all folks. I think that was one of the real reasons I came to this country. I really wanted to see what democracy was really about, having lived and been brought up in England. I was very loyal to my country. I've only just in recent years become a citizen of the United States, for a lot of reasons, actually, but the main one was because I didn't feel that anybody had the right to take my birthright away, and I still feel that way.

I feel I'm a dual citizen. I was born in another country, and I'm a foreigner there, and I have immigrated here, and now I'm naturalized, as we say in England. I feel very, very loyal to the United States of America. I don't feel that I--it's just that I'm born somewhere else. I don't feel that has any bearing whatsoever on my loyalty or my need to feel American. Sometimes I feel very American; other times, I don't

feel American at all! Some people might say, "Well, you've got to," but that's how it is, how I feel.

But I also believe that my civil rights are now in concrete, just like anybody else in this country. In the beginning, they weren't. I mean, I couldn't vote, I couldn't really voice my opinions, even though I did a lot [chuckles]! I just tried to do whatever was right by all folks. I felt then, and I still feel now, the right thing to do is the right thing to do; we have to live by the rules of society and stay within the laws. And we have to, I feel, expose people that don't live within the rules.

Drucker: And also make the laws, right?

Steneberg: Make the laws, too. Or help to make the laws. I shouldn't say we make the laws, help to make the laws, both at the federal level and at the state level.

Drucker: What kind of opposition did you encounter in the early days of trying to get things changed, from either family or friends, or community?

Steneberg: Oh, everybody felt I was crazy, mad. That nobody is going to listen to you, one person. I know that. "Nobody is going to listen to one person. You have to unite, and you have to be a whole group, and you have to be all saying it together." It's definitely a democracy that's run by the majority. You see, I don't really believe we're a majority anymore. So many people are so lethargic and don't see it as their civil rights at all to vote and do all these things to participate, and they blame the government for everything, and they are the government! They don't understand process. That's my whole impetus--one of the things--for coming here, finding out really what the process was, and understanding it and working with it.

Drucker: So you based all of your work in the disability community on the democratic process. Was this something that you read and learned about and applied to the disability community? Or was it separate from that?

Steneberg: Well, I suppose in the beginning it was separate from it, but I then could see that the processes come together. One thing always has bearing on another, and one thing leads to another. The process of anything that we're involved in--civil-rights-wise or in learning and in exchanging ideas--is contributing to bringing about what we see as a democratic society. I believe it will work if people let it work. But corruption and lies and all these other things do get in the way.

It is very hard not to fall into that way of life of corruption, too, because suddenly you're working on something and you find that you're in with all these people that are very corrupt, and then you have to back out. It's kind of a difficult process. Ideally, it's a great process, but it's not so easy to put in place. Ideally, it's a dream--I think--I feel. I believe in it, but it's still a dream, that if everything were perfect (which it never is), how it should work. It would work if everything were perfect, but everything is not perfect and everything is not possible. Corruption does get in the way. It's very difficult to really, clearly achieve completely, unfortunately, a good democratic society.

That's my conclusion. I may be totally wrong. I might have jumped the gun on something. I'm still learning, you see. Every day I learn something new. Every single day. It's just sometimes a very little thing. Sometimes people don't see the relevance of it, but it's every day. I just learn something.

Drucker: In the early days, when you were getting involved with the disability community, who really influenced you or helped you along the way?

Steneberg: People who influenced me along the way are so numerous I could never tell you. It started right off when I was small, as a child. I can remember a math teacher saying to me once, who was very good, and she also had a lot of insight, she said to me, "Go live your life, but don't kill yourself doing it." She was just one of the people, right in the beginning, before I ever got into any of this, who helped me to see more clearly what I should do. She was pushing me in the right direction, but she didn't feel it was worth killing yourself over.

Then all along the way I've had friends. I've been very fortunate, actually. I've had wonderful friends who I suppose had a loyalty to me--it's kind of difficult to say that, but when I think about it--and have always supported me, and have been very faithful and loyal. I have no idea why. A lot of people feel, I think, that I'm a leader. I don't know. I haven't really thought about it a lot.

It's just unbelievable the people that have tried and have helped me. Even you, Julie. You help me all the time see things more clearly and show me the way and show me what I should do. It's because I'm inquisitive and nosy, I suppose, and am looking for something to do.

Drucker: Did you really see your qualities in a different way when you had to start fighting the "establishment"? Or did you kind of

know yourself before in that way? Was it a surprise to you? Describe how in those early days what your day was like, if you can, and the fight that went on, and what it was like, if you remember.

Steneberg: Most days it was like there were questions all the time because I didn't know whether we were doing the right thing. The only thing that was law, when it passed, was the Education for All Handicapped Children Act. It was passed in 1975--was on the way to being passed in the seventies--and in 1975, at the end of the Nixon administration, Ford eventually, when he took the presidency, signed the Education for All Handicapped Children Act, under a lot of stress and under a lot of pushing by all of us folks who were out here in the trenches, in the grass-roots, as we say. We were pressuring them to sign this law.

Parents all over the country had had their children in various schools, which were very segregated. They wanted them to go to school, and the kids wanted to go to school. They were denied those rights to go to school, for all kinds of reasons, but mainly because they were in special education, and they were considered children who weren't worth educating, for whatever reasons.

Drucker: You said kids were denied going to school. Kids were denied entrance to integrated classrooms, or they were denied going to school?

Steneberg: To school, period.

Drucker: So what did parents do with kids?

Steneberg: They were either in institutions, or they sat at home or they went to these special schools, these very segregated special schools or places. They weren't all schools, these places. These children were considered not worth educating. Now, you and I know a lot of people who are disabled, yes, but they're highly educated and they're also able to hold down jobs and to work, not necessarily in the ways that we would think of ourselves as working, but they definitely can do certain jobs of their choice, that they want to do. And they're given the opportunities to go to school and learn, like everybody else.

I know, and you know, people who don't have any verbal language who also are brilliant inside their minds because they are able to figure things out, they're able to teach themselves. I think a prime example of that, believe it or not, is people who have autism. I don't like to be so controversial, but autistic children who have only lived in

institutions have taught themselves to read, very often, because with facilitated communications they can now communicate to the world as they never could communicate before. I believe--I might be completely wrong about this--it's because they've been stuffed or stuck in front of a television screen, and they've watched it day in and day out, and through repetition they have been able to teach themselves to read.

That says to me that everybody learns differently, and everybody can learn something. Just because it's not the conventional way, it's worth doing. It's ridiculous not to give them an equal opportunity.

Drucker: So until the law was passed, or even after that, Susan was still in segregated classrooms?

Steneberg: Yes.

Drucker: Tell me a little bit about what you had to deal with as far as the first few years. Was it the state, city level, county, state level?

Steneberg: Well, it was all the levels you are talking about. Everybody didn't see the point in letting her go to a normal school--or anybody else, for that matter--disabled children were not worth educating.

Drucker: But Susan wanted to go to a regular school.

Steneberg: I don't think Susan really knew at that stage of the game. Susan just wanted to be with other kids and play with them, and whatever. I don't think she could determine what she really wanted. She can tell me now what she wants to do, but--

Drucker: How was it with the other parents that had kids like Susan? What kind of reactions did you get? Was there support? Was there not support?

Steneberg: That is a very difficult question to answer. I think deep down, people believe that their kids should have a normal life and all that, and they might say that. But they don't necessarily, deep down, believe it is possible, mainly because they've been indoctrinated by the society that we live in. If you come from the old school, which a lot of us do, you've been taught that disabled kids need to be taken care of, and in some points that's true. I mean, you need to have protection and safety built in, and all of those things but that's a need for any kid. It's not so different for any child.

So, I think it's a difficult question to answer. Very often, people go along with you and say yes, they're for inclusion, but they don't really understand what it means. Sometimes, when they do, they hesitate about what they think it should be and what it isn't.

Drucker: Who were your allies back in the early seventies, when you were trying to get all these changes made?

Steneberg: Well, it's interesting that you should ask me that, because in the early or middle seventies I met up with another parent whom we both know. Her name is Diane Lipton. She was in very big distress at that point, mainly because of her husband. I think personally--and this is just my opinion--it had made him absolutely crazy that he had had three children, because Diane had triplets, two of whom were dead when they were born and Chloe survived.

She very quickly joined a group up at Hilltop, and was one of the first people I talked to, support-wise, and he kept saying to me, "What are you going to do about it? What are you going to do about it?" I used to get pretty annoyed at that. I used to say to him, "What are you going to do about it? Not what I'm going to do. What are you going to do?"

Drucker: "What are you going to do about it," like what?

Steneberg: About the whole situation, with these kids. I was a little perturbed. Yet I wanted to be helpful and talk to them. Over time, we became firm friends. We really did. We've been together ever since in this whole thing. We worked at this. We turned our lives around. We have changed our careers into these training parents of disabled kids who in the beginning were a pain in the neck--are still a pain in the neck to some people--and we have done a lot of things, although we've always managed to unify people and bring them together and get groups of folks to do these various things and organize people.

Drucker: What year did you stop nursing and devote yourself to really becoming a parent advocate?

Steneberg: Well, that's been a gradual process, mainly because of the fact that I had to earn money and there was never any money in the nonprofit business that we live in. I had to work part time for a long time, and I was a volunteer--still am. I suppose that's where it's at, still. It's not possible to say when exactly. It's been a gradual process. I worked part time, and I worked part time in a doctor's office towards the end, and

since that time I've not worked. So anyway, it has been an ongoing process.

More on Childhood Disability

[Interview 2: February 17, 1999] ##

Drucker: I wanted to ask you what were your symptoms as a child? You had talked about your illness, and I just wondered what your symptoms were.

Steneberg: I assume you're referring to my symptoms around my lung disease, because it's a little difficult when I've talked so much about various other things, to know quite exactly what you want me to address in this question. Okay, let me think. The symptoms as a child were I was a sickly child. I seemed to spend a lot of my childhood not actually in hospital, but in clinics. It was during the wartime in Great Britain. We were mainly in Wales, actually, in Cardiff, that I remember vividly. That's what I will relate to you here, but it was similar situations over many of the various places that I lived when I was a young child.

My mother, who was an ex-nurse also, was very into trying to find out what was wrong with me. In fact, I would go as far now as to say it was an obsession with her. But anyway, that's beside the point. The point is that I did spend my childhood going around to what were known then as TB clinics, tuberculosis clinics because during the war it was very rampant, and a lot of people did have TB.

As I had a shadow on my X-ray--of course, you must remember, this was the early days of X-rays--it showed just like a white shadow. Everybody was very mystified by this, as I was a young child. So that was why I'm saying to you that this is the reason for me giving this long explanation.

Drucker: When you say "sickly child," how did you feel--I mean, I know you talked about how you felt, that you didn't feel any different from anybody else, but were you tired a lot? Were you coughing? Do you remember different feelings that you had?

Steneberg: I don't remember that I felt any different. I think the other people rather injected those ideas into me with regard to "You feel this" and "You feel that." I don't know that I remember feeling overly tired or any of those things, but I might have

been. I mean, I can't verify that. That's why I hesitate to relate this precisely because it's difficult to know what one can remember when one is very small, because at certain stages I was very young, and I don't know what I remember and what I don't. So that's my hesitation.

I also, however, do know that I went through these clinics, and every time that I went through the same kind of regime and rigmarole, as I would say, it always came up very negative, in the sense that I did not have TB. They didn't know what I had, and they would say, "Oh, take her away. Just look after her, and she'll be okay," which probably would have been true, to a point. But as you know, it progressed over many years, of which I'm now at the ripe old age of sixty-two, nearly sixty-three.

I'm just telling you all this because I was not expected in those days, I don't think, to live to be this ripe old age, and so that is one advantage that I have had, obviously. But now I'm looking at other things in my life, and I'm trying to record this because I feel that it might be important at some stage for all kinds of reasons.

I don't know whether I can answer your question precisely, Julie, because of the reasons that I just told you. My memory, for instance, going back to when I was very young. But anyway, it all came up negative, and I was able to carry on with my life, even though I was reminded constantly that I was imperfect, I suppose, something along those lines, or there was something wrong with me.

I don't know that that really sunk into my own life and memory and everything else, because I just did everything that I wanted to do and felt better for it, quite often. Exercise and activity which I did made me feel better. Sometimes I'd get tired, but everybody gets tired. I would just rest, and I would go back to whatever I was doing.

The only thing that really was hard for me was keeping up at school. I became very depressed and upset at times around not only the inadequacies of the system, which was in England, of course, but also the fact that I was not at anything like at grade level. In some subjects, I was just unable to participate anyway because of my limitations, and they weren't physical. I did not have the mental capacity or the academic background of my younger classmates, or my equal classmates, I should say, because I had not had the background and the necessary previous schooling which was required to be able to be at grade level.

Also, there was a tracking system in place in the educational system in England. You either went into the academic track, or you went into the vocational educational track. I was geared to what was called the secondary level, which was the vocational educational track, which I did under great protest because I did really want to do all the more academic courses, etc. So that became somewhat of a hindrance, too.

Drucker: You wanted to do the academics.

Steneberg: Some of them. For instance, I wouldn't say I wanted to do French, but as I ended up in a French convent, it was a requirement. It was a terrible time for me, as I much preferred to be out playing basketball or doing some gym activities or something like that, other than academics.

Drucker: Did your experience with the tracking system and your experience in school in England affect how you started working with the schools here around Susan's placement and disability? Is there a connection there?

Steneberg: Oh, I think indirectly there is, yes, because of the fact that I had to strive to obtain what I felt I required, whether I was successful or not. That is a big mistake that I think a lot of people and parents particularly make, which is they don't allow their children to fail. You have to be able to try and accomplish something, if you really want to do it, and you have to be able to deal with and cope with failure. Failure is a very important thing.

We have to allow our children and ourselves, and anybody else that we come in contact with, other children too, we have to allow people to fail because you can't win all the time, and it's very necessary to be able to learn to cope. To do that, you have to, as I say, be allowed to fail and not be reprimanded or kind of tormented about it, if that's possible.

That's why I'm saying that and expressing that feeling because, I was allowed to fail, and I did many times. Then I kind of gave up and said, "Oh, well, I can't do that because," whatever the reason. I think that helped me a great deal. I really do.

Drucker: Did you see that happen with Susan when she was small or in later years? How did you see that played out with her life?

Steneberg: Yes, I think I did see that in her life. I would come to terms with that myself by saying, "Oh, well, she couldn't do that

because it's not possible. She's going to skip over certain things." Everybody seems to put people in boxes for some reason, and they feel that they'll do things in sequence, and that is not always the case. I have never found Susan to do everything exactly like everybody says she would do, in a sequenced way.

I think there are gaps in people's mentality. I think there are certain things you jump over, you don't ever do. The one that's very pronounced to me is that Susan did not walk till she was nearly--well, on her own and by herself, without holding onto somebody else's wheelchair or something like that --till she was nearly seven years old. I just feel that there are certain things that you just suddenly get up and do, and there's been no sequence. There are just gaps and you jumped over them somehow. Don't ask me how; I don't know. I just know that that has been the case with her a lot.

Like now, she's suddenly very verbal. She never was before. She tries very hard. She gets frustrated, but she tries very hard to express herself in an understandable way for everybody else, but she's not always successful.

Drucker: Would you find that you had expectations for her that you had to deal with? Like the expectation for her to be at a certain level or just be a certain way, and then if she didn't, did that happen?

Steneberg: Oh, yes. Many times that happens. It's still happening. Now she's twenty-eight and she's living in supported living, away from my house, away from our home. She has her own apartment. She lives with a roommate. The people she comes in contact with, she mimics them and imitates them, so much so that it sounds like that person sometimes talking to you, not Susan. It's very noticeable sometimes. Not always, but sometimes.

So she's really a person who learns by what she sees other people doing and by copying, I suppose we should call it. When she sees other people acting in a bad way, then she's sometimes inclined to copy that, too, and behavior-wise is reprimanded for that, or that's dealt with.

It's not all good, but it's really the way she learns. For instance, she has an obsession about repeating things over and over again. Things that we have taught her once, she still says, sometimes without any meaning now, but then it gets less and less as time goes on, but you can hear her, if you know her well, repeating things that were taught to her when she was very young.

Her long-term memory is excellent. Her short-term memory is not as good. It would be more helpful if it was. I think that sums it up the best I can.

Disability Rights as a Civil Right

Drucker: I'm going to go back a little bit to the early seventies, the movement. I know it's a long time ago. When did you realize that disability was a civil rights issue?

Steneberg: I think that that was taught to me mainly by several of my friends who are still working in the field--some of them now are lawyers; some of them aren't. It depends.

Drucker: Who, for example?

Steneberg: Name names? She's trying to get me in trouble now! Legally, name names. I'm just trying to think.

Drucker: This question can also be about who influenced you quite a lot. When did you realize that it was a rights issue?

Steneberg: I came to the conclusion that these were rights for my daughter, and also for myself, because regardless of whether I wanted to admit it or not at this stage in the game, which was 1970, I probably was still in denial in a lot of ways with regard to my own disability. I think I've only really come to terms in more recent years--maybe the last five or six--with the fact that I am a disabled woman myself. I think the parent movement, which I've worked in all this time, has brought that out to me more than ever.

Now that I have physical signs which--you know, I'm walking around pulling an oxygen portable tank and doing a lot of other things--I think it's more in my brain now that I really am a disabled person, whereas before I kind of tried to deny it for a long time. Even now sometimes I'm kind of in denial at various times around different things.

In the 1970s, when I first sought help from the Center for Independent Living in Berkeley and was introduced to the whole legal aspect of this whole movement, it really dawned on me that it was a civil right, and that it was my daughter's civil rights, came more to mind at that point. I don't think it really transferred over to my own civil rights till much later, but I can't exactly tell you when. But it was around

about the same time, I'm sure. Even if I was saying it and wasn't really firmly believing it, I think that was the time that I came to really realize that this was a movement and I needed to be part of it, and joined in.

The other thing about that is, and I suppose it was the early seventies, no, it was not so early, actually. It was about '74, '75--somewhere in there--because the Education for All Handicapped Children Act wasn't passed till about '75, early '75. I'm just trying to think. It was 504 [Section 504 of the Rehabilitation Act of 1973]. Julie, you know the date.

Drucker: Seventy-seven.

Steneberg: Seventy-seven? So it was between '75 and '77 that it dawned on me that this was my daughter's civil rights, and also my own. It's somewhere in that area, or range of years.

Work on the Passage of the Individuals with Disabilities Education Act [IDEA]

Drucker: Do you remember trying to get the IDEA passed? Tell me if I'm wrong, but I think you helped write some of the legislation for that amendment. Is it actually an amendment?

Steneberg: It's a little difficult to say. The whole idea, when the name changed from the Education for All Handicapped Children Act--well, that was a long time coming. It was talked about by the movement for a long time before it actually got into legislation. The act changed its name, and it was an amendment, like you just stated. It was an amendment to change the name, to do many other things as well, not just change the name. That's when it became IDEA [1990]. It's the Individuals with Disabilities Education Act.

Drucker: How did it change from the first Education for All Handicapped Children Act to IDEA? Were there changes that you wanted to see in it, were they in there in IDEA?

Steneberg: Yes, a lot of them were. Of course, some of them weren't. I mean, you win some and you lose some in these exchanges of ideas. That's why we were very adamant about not re-opening it up this time. When I say "this time," in the last two and a half years. Well, it's nearly three now because the regulations are still not out. Just to put that in perspective, these things in law seem to take forever to get in

place. When I say "forever," some people would say, "Well, it's not forever; it's only two or three years." To me, that seems a long time, and it seems like forever.

We've been working now for the last three and a half years on the latest changes in IDEA, which is basically fighting with Congress and with many other bodies throughout the United States--even some of them parents and agencies who we work very closely with--around issues of inclusion, discipline, and there was one other thing. Oh, some of the more intricate LRE issues, which are to do with the least restrictive environment.

There are many factions within the movement, itself--of learning disabled people and also physically disabled people, and mentally retarded individuals--severely handicapped, I should say, severely handicapped individuals, or people who represent them about the interpretations of all of these things. Of course, they're all looking at it from different angles, particularly parents.

Parents want what's best for their children, and usually what's best for their children is where they're at right at this present time because they don't have the ability, particularly parents, of looking into the future. Nobody does, of course, but parents are especially not willing to take chances, I think. We've had a very hard time over the last few years, trying to just sell the idea that disabled people want opportunities to be included in society. I think that was really driven home to me, the more intricate detail of what is really meant by being given opportunities to be in the mainstream.

Parental Fear of Changing the System

Drucker: What do you mean by parents not taking risks?

Steneberg: Parents are very loathe, on the whole--not every parent, but a lot of parents, on the whole--are very loathe to do anything which they think might jeopardize the situation their children are in now. I say "children" with tongue in cheek because a lot of these people are elderly people who have their children in institutions. The reason I'm mentioning this is that a lot of individuals--they are individuals--and they really would like to be out of those institutions, and they will tell you that.

I have been to one or two institutions several times, and the same people are still saying the same thing to me when I go there. It's very distressing and frustrating. The only reasons they're kept in those institutions are either because the state is the ward of the individual, or the individual is the ward of the court, I should say. I'm just telling you that all their parents want them to stay there. It doesn't matter how you talk to their parents. Of course, you can go to court and do all that, but you're more likely to lose than win, mainly because there are lots of things that are factored against you or set up against you.

It's very difficult to say that an institution is not the best place for an individual. Sometimes maybe it is. But if they are not allowed to fail--as I just previously mentioned--then how do you know? How does anybody know?

Drucker: I have two questions regarding the parents of the people who are in institutions. Do you think that the most important part of educating parents to help their kids get out of institutions is to emphasize disability as a civil rights issue, or to emphasize their ability to actually change the system? Or both?

Steneberg: That's a difficult combination of questions.

Drucker: It sounded like you were saying that the difficulty in changing the whole system is because the parents don't take the risk, so it's as if you're saying the parents could actually change the whole system if they wanted to.

Steneberg: That is correct. They could change it if they wanted to, if they would become unified and would see that they have to take chances, or let their children take chances. Let their young adult children take chances, I should say. But they always treat them as children, whether they're old--some of these children that I'm talking about are fifty years old--and their parents starting on eighty-something, or ninety. I'm just telling you that it's kind of difficult to classify these people altogether, and I shouldn't do that. But they all have the same trend and the same thoughts, that they want their children, as they call them, kept where they are. They're better off in the institution.

Some of those disabled individuals don't feel that. They want to be allowed to do other things. It's shown--there are pretty good studies now--that people do better when they live outside of institutions. They might not live as long, it's true, and there's been a recent study over the last few years

on that, that they probably die younger when they're in the community, but that is neither here nor there. If you're not allowed to take chances, how would you know that, either?

If you did stay in the institution, there's no guarantee, either, that you would live longer. So it's kind of like apples and oranges, but if you're not allowed to take chances, how can you tell that? Or allowed to fail, as I would say.

Drucker: Have you got around to different groups of parents who have kids in these institutions to meet them and talk to them? What has been your experience?

Steneberg: On the whole, I have had some experience trying to do that. I have not been very successful at that, mainly because the parents won't let you be. They don't want to hear. They're very closed-eared, I suppose I should say, about that. Their mind is set, and they have decided, and that's what they want, the majority, not all of them. There are many parents who--I must emphasize this--who, over the years, and it takes years, do a complete turnaround. I can name probably a handful of those people.

I'm not going to give you all their names because some of them are dead, but I could point to one lady who I, at one time, felt was a very big barrier to all of this, of opening up the parents and institutions. I still know people who are big barriers to any of this ever happening. But this one parent was a remarkable woman who would admit that she was scared and she turned around at least 85, 90 percent, with her daughter.

Her daughter now lives in the community, lives in a roommate living situation and has been, I would consider, somewhat successful at living in the community. She goes to college, which she always wanted to do. That's the first thing she wrote. Another controversial thing which was tried with her was facilitated communication.² I can't go into that right now, but it is a form of communication that some skeptics believe very strongly that it is not the actual client doing these things, but it is the person who's facilitating. It's a very controversial issue, which I can't get into right now.

² In facilitated communication, a trained assistant provides communication assistance by supplying necessary physical restraint, guidance, or support while the disabled client uses a pointing or typing device.

But it does exist, and this person, this daughter of this person whose story I'm relating--the parent's story--the mother did a complete switch, I think, because of her daughter being able to communicate. Her daughter was nonverbal, and many of these people are, and some of them are autistic or have autistic symptoms. I don't know if I can say they're autistic because I don't know that for sure. They have a lot of autistic-like symptoms and usually are nonverbal. They use facilitated communication once they understand how it works, to be able to do remarkable things, such as typing and getting the message out. It's really remarkable. With today's technology there are all kinds of machinery which they learn to master quite rapidly, and they are able to communicate at least with their own parents and teachers and friends.

Drucker: Would you say that you really influenced this parent to help her make the 90-percent turnaround?

Steneberg: I don't think that I influenced her anymore than her daughter did. I think the main influence for this person was her daughter, the actual fact that she could see that her daughter was able to tell her what she wanted. I'll just tell you what she communicated, because it's very powerful, I think. One of the first things she wrote out, in her mother's presence--I don't know whether she meant it to go to her mother; I think she did, by what I'm told--was the fact that she wanted to go to school, and she wanted to go to college. She even worked that out. She wanted to go to school to make up her education that she had missed.

Now, I think that's a very powerful message for somebody who can't necessarily spell correctly by "our" standards, but it was made out to read that way. I think that's a very powerful message for anybody to witness, whether they're a parent or not. But this parent definitely witnessed that.

Drucker: What was this girl's schooling? Had she been in an integrated classroom, or this was before integration?

Steneberg: This was before integration. I don't know that she had spent any time, really, in school. I don't know how long she had been in the institution. I know she'd been there a long time, but I don't know what school or what she learned.

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Steneberg: I believe very strongly that people who were institutionalized cannot--some of them, anyway--cannot sit and just be doing nothing, even though it might appear that way. They must be

learning by what they see. They must be learning, self-teaching themselves how to do all kinds of things. I can't even begin to name what. This individual--this is only one individual I know, but I not only heard but I've witnessed others--who obviously have learned quite a bit over the years particularly around reading, spelling, and understanding what people are saying to them. Whether they can hear or not, I don't know that. That's questionable. But that is very powerful to me to say that the individual is smart, and they're trying to communicate, and they have not been able successfully to do that until this time when, with a bit of facilitation by somebody who knows the individual very well, they can make themselves understood.

That's the controversy because that's where it comes in. A lot of people say, "Oh, no, it's the person who's doing the facilitating that's doing the writing," and won't give credit to the actual individual. I don't necessarily believe that. That's why it's so controversial.

Movement out of Institutions

Drucker: Do you think the next wave of the movement, of the disability movement, will be trying to get all the people who are in institutions out of institutions?

Steneberg: That is not the next wave; that has been the wave for the last ten or more years--ten, fifteen, something like that. Some people in the movement have always had the vision of inclusion, particularly people who are quite well known now: for instance, the assistant secretary of education, Judith Heumann, who took me in in the beginning, and Diane Lipton, who's the other parent I have come along with for many years. She's now an attorney, specializes in this field, and is extremely knowledgeable. I would go as far as to say she's the most knowledgeable person around this particular law in the country. Other people would argue that, of course, but I believe that.

The intentions of Congress and all that are very apparent to both Diane and myself, for that matter. I also feel that I have grown up with this for so long that I just feel that the intentions, the original intentions were to allow people to participate at whatever level they could in society, they're given the equal opportunities that everybody else has.

That's what we base our belief on. And we know, from our own experiences with our own children, because we both have severely disabled children--mine doesn't have the physical limitations that Diane's has--but they are very similar, similar and yet different, in their abilities to understand and communicate. So it has become a very big learning experience for me, with at least two severely disabled people directly connected with me. And Diane, of course.

Day Program for Susan, 1971

Drucker: What was the day program, the first day program that Susan was going to go into? What was the setup like? What was your reaction to it?

Steneberg: Oh, Susan was placed in a very segregated environment in the beginning. She was in a treatment center or day care center, yes, a treatment center. We might talk about it like a special school, which is what it was considered. It was for very young children. I mean, it was a nursery situation in the beginning. She just progressed from there into the next class. It wasn't till she was about in the second or third class, when she graduated age-wise, because she was kept in pretty age-appropriate programs, most of the time.

She went out of the segregated program into a more integrated program and, for all kinds of different reasons, people said she couldn't make it in what I term the least restrictive environment, but she wasn't allowed to try it sometimes. I mean, it was kind of that situation because people had barriers or discriminated, but they didn't know why they discriminated necessarily. They didn't think those children had a place in society, and they believed it so strongly, and they were in a position of power, of course, so that they were able to put that in place.

And so she was thrown out of the school--

Drucker: You mean the school administrators and teachers discriminated against her?

Steneberg: Yes, exactly. Administrators and people in positions that had power, that could look at written reports, etc., and interpret them the way they wanted to. It usually was in the negative. But I still went on about my business, saying that she learns by what she sees other people doing. I could demonstrate

throughout her career in education how she deteriorated when she was only with other handicapped children, and how her behavior got very much worse, difficult to deal with. She would have some really bad behavioral things, like being very mean and biting people and even biting me. I mean, it wasn't just other people.

It was very helpful in some ways--even though painful in many ways--to understand that. Emotionally, it was very taxing.

Drucker: You had to fight all along the way, every step of the way to get teachers and administrators to listen. Did they listen at all? Had the law been passed?

Steneberg: The law had been passed. In the beginning, certain people said, "Oh, this will never pass. It's going to be too expensive. It's this, it's that." And there was always an excuse. But it did pass. I don't think they still owned up to the fact or admitted the fact that they had been a big thorn in my side or anybody else's, for that matter, because they were just so against integration of disabled people into society.

In fact, people still say things which are very hurtful and very absurd when you think about it, such as, "those people need to be in those schools, and those people don't need to be in these schools." I mean, that's the trend even now, as we talk. There are amendments to laws right now, as I'm sitting here talking to you, which would put inclusion back twenty years if they are allowed to pass.

There's one Supreme Court case [Olmstead v. L.C., June 22, 1999] which, in some ways, I hope it's not heard and the district courts' decision stands, that is, right today in 1999, pending in the Supreme Court. It will be devastating to the least restrictive environment of people who are in society--all disabled people. If we don't get people motivated to start a revolution around this issue again, we will be lost forever on this issue, until we can get it overturned.

It's very depressing and very frustrating to think about, but that is the fact. Today, as I sit here, in February 1999, it's a civil rights issue. It really is.

Implementation of Laws

Drucker: What do you think it will take for the changes that were made in the seventies to happen now?

Steneberg: Well, the main thing that needs to happen now, with regard to making what happened in the seventies really stick for all disabled people, is there needs to be more and more implementation of the law [Individuals with Disabilities Education Act, 1990]. There needs to be put in place in February 1999 and from then on, particularly during the rest of the Clinton administration. It's politics coming into it, it does come into it. It's very much part of the political arena, even if on the fringe. It's very much "Let us in, we need to be in society and we need to be in there now, not ten years from now or anytime from now. We need to be there today, with everybody else." To do that, it is very, very important that people are held accountable. Not only accountable, but enforcement has to be built into this law.

Unfortunately, when IDEA was crafted, a big section that was not really put in place in this law was the consequences which happen if you break this law. That's a big statement, but I want it to be as broad as it can be because it's not only the kind of discrimination that we all understand, it's also the subtleties and the attitudes and the intentions that are inflicted upon people to hurt their self-esteem and everything, particularly children. Children are influenced so much that it's very easy to warp the mind of both regular education children and special education children. So easy to do.

Positive attitudes need to be brought out constantly, and children particularly need to understand that they have to think good about people. It's okay to get angry, it's okay to respond, and it's okay to do certain things. Blowing up, for instance, and then letting go. But that all has to be taught. They're all tools which we all use every day, and they have to be taught and instilled into very young children, starting very young. It's hard to do that. People are not eager to do it, and won't necessarily do it because they think it sometimes sends the wrong messages. But I think it's very important for it to be addressed early and to be followed through.

Drucker: Do you mean that disabled kids are not being taught that they have a place in society like everybody else, even though inclusion has been part of the law?

Steneberg: That is correct. There are certain people who will not teach those kind of things and won't address them in a class. The prime example is you go to the store and people will say out loud, so you can't but hear, "Oh, don't look at that kid." For whatever reason--it doesn't matter what the reason is--they will say that to their own child, so then their own child gets the message that we're not to look at those children, we're not to look at those people. They're different. They're not to be looked at.

It's like racism. It's so similar. In fact, that's what we allied ourselves with very early. When I say "we," the movement--of running alongside--segregation, integration, whichever way you want to put it--civil rights movement. We looked constantly at the Brown v. Board of Education, and we ally ourselves constantly with things that came out of that civil rights struggle.

But nobody ever has gotten to the point where they can enforce--particularly in IDEA. IDEA addresses education. It's in schools, and it has narrowed down a lot, actually. It could be addressed, I believe, in a realistic way, if more people would freely come out and speak against--not only by doing lawsuits but by just speaking out about other people administration-wise, in school districts, colleges, universities, wherever it happens--against the discrimination. If people would come out and talk about it and put it on the table, as they say in this day and age, and address it constantly, it would get less and less acceptable, I believe.

I don't know if discrimination would ever die out completely, but there's all these people that have biases and attitudes about certain things. But it would help tremendously if people would just do that. But then there are other things which you can do. There's got to be some enforcements of the law. The penalties have got to be severe enough for it to hit somebody, I always say, in their pocketbook.

I don't know that that would necessarily do it for some folks, but it would be a long way. If you held up an administrator's salary and didn't pay him for five weeks, ten weeks, six weeks--whatever amount of time--and said you wouldn't pay them until they succumbed or go to court or whatever to get it fixed, as it were, then I would feel that we had gone as far as we could go with enforcement. But there have to be some sanctions put in place, for enforcement, around people's behavior.

Drucker: Do you think in some way that if enough people in society start acting decently towards everybody, including everybody with disabilities, that the other folks would start to copy that? Sometimes I feel that's what happened in the seventies and sixties. People saw a shift in attitude and started copying that. Do we need laws to change people's attitudes about difference or is there another way? Do you think that it has to be through a law? Could a law actually change attitudes that way, only through enforcement?

Steneberg: Well, I think there needs to be both. I think there needs to be enforcement in the law itself, and that would take amendments, and probably penalties wouldn't be severe enough for me, but they might help. I'm not saying they wouldn't. That's one way of dealing with it.

The other way is that attitudes of people would start to change over time. It would take a long time. But over time, attitudes would change because we've seen change already--not a lot, but some--from the seventies to now, with some folks, if not with all folks, and definitely not with some of the more conservative people who make the laws and some of the legislators at the local level, at the state level, at the federal level.

It's not the laws only that are going to change these things. It's going to be a combination. The combination has to come one from the other and play back on each other, piggyback on each other, I should say. So that's important to realize. It definitely would be a way, if everybody was on the same page at the same time, trying to think people are different, nobody's the same.

For instance, sometimes when I'm watching television--I hate to keep going back to that, television, I don't think I brought it out before--I feel a lot of the autistic children learned all these things from television, the only media that is in all these institutions. When I've gone to institutions and various places, even schools--the one thing that is in all these places and is on from time to time is the television.

Television is the common denominator, as I see it. I might be completely wrong, but the common denominator is that the television is on. You visit the institutions. Everywhere you go, there is a set, and there are individuals standing, watching it. It doesn't matter what it is--whether it's a football game, whether it's lip reading--I don't know what they're doing, but I'm just telling you that somehow that media so engrosses people that I believe it's the main tool that has

helped people in this time. That's saying a lot, because I am not an avid TV watcher. I'm very, very fussy about what I watch.

Drucker: I wonder if that could be the tool to change the rest of the world's attitude.

Steneberg: I believe you're right, but it's got to be a lot more positive around disabilities than it is at the present time. Everything on the television at the present time is so negative.

Effects of Parental Advocacy over the Years

Drucker: Who and what do you feel you influenced the most? I know you probably will say Susan, but I just wanted to ask what changes you helped make over all the years?

Steneberg: This is a very big question. It's in so many different areas that it's hard to pinpoint which is the biggest, or whatever your question really is. I've made a difference, I believe, directly on my own family. The prime example is my husband was so conservative. He believed very strongly, in the beginning, that Susan did belong in an institution. He would say that. Well, he might not say that very openly now, but that's all he knew. That's all he had been trained and taught to understand about severely disabled people. An institution is the place; that's where they belong.

Well, it's like the previous person I was talking about, who had done a 90 percent turnaround. I believe that he would go as far as to say that he had done at least an 80 to 85 percent turnaround. I don't know that he would say he'd done--because he's a very precise person--a 90 percent turnaround, but I think he would agree that it was at least 85 percent. But that's neither here nor there.

That's one person that I know that I've really helped to influence. It was not only me, though, in that case. My daughter, Jennifer, is a very liberal-minded, democratic type of person who believes everybody should be given a chance at least to participate. If they fail, they fail. If they don't, they don't. But any success is some success. We make a big fuss about it. My daughter is constantly being cheered for her achievements. That's what we believe in: positive attitude. People do what they can do, and, hopefully, will reach their full potential in certain areas.

Anyway, to get on with the thing, the other people I've influenced, I know because people tell me, not because I really feel that I've done so much, just because I feel some satisfaction from going out and doing trainings of parents. There are always parents in audiences that say, "Oh, gosh, you taught me so much." It's not really me. It's just showing them the way, showing them the fact that they have these rights, that there are civil rights, and to demonstrate to them what the differences are between rights and your civil rights. You have to work very much harder on that, in that area.

Civil rights are difficult to demonstrate for many people, because they connect it--like we did, I suppose, in the beginning--alongside the Education for All Handicapped Children, you know, and people who are different. Civil rights around race issues and religious issues and age issues and all of those things which are now a part of our civil rights. Women's issues and all of that.

It's kind of like a whole different aspect of opening up the world to some people because they have no idea--people have tunnel vision, and believe what they were taught when they were kids--and that's why I believe so strongly in teaching kids to be as flexible as possible, and also to be as open and look at all the options before they make decisions. Those are the goals.

It's very hard to get that message across, particularly in one small training, but it is possible, and it's achievable, but it's difficult. I have reaped satisfaction from many, many trainings. Even if it's just a small number of people, I feel that I've done my job, because one or two people learning about their rights and their civil rights and what the law really says, and all of that is an achievement. It's nothing to be sniggered at.

One parent, going back to her family and her community with knowledge and the empowerment to keep inquiring and looking for more information and proceeding--at least not standing stagnant and being in a rut--that is an achievement, as far as I can see it.

I don't think those should be treated lightly. I feel that that's important, even if it's just one individual, make them start thinking for themselves. It helps. It really does. That's how I feel. In small communities--rural communities, particularly--it's important to reach out and teach them how to reach out, tell them who to get in contact with, or give them as much knowledge as you possibly can--not always right

knowledge. Sometimes it turns out that was bogus, or you led them up the garden path.

You have to accept those responsibilities when they come back at you, because sometimes they do, and say, "Okay, well, I made a mistake," or "They must have moved," or whatever the situation is. Just be truthful about it and keep an open mind and say, "If you do this and you go here and you go to this area board, or you go to some other agency, they will help you find what you need." Directories, catalogs, whatever.

Well, of course, in this day and age, it's easier for some folks--not everybody--to get online or to use the computer. A lot of people, however, do not have those skills or they don't have computers in their community, and they're not able to do that. But I'm just saying on the whole it is somewhat easier for certain folks to keep in touch and to communicate.

Gathering and Using Information

Drucker: Do you feel that all the experience you had has built on the work that you do now, and all the years of your saying that just because it doesn't happen, you just have to be truthful? Have you learned from all the things that have happened over the years?

Steneberg: I've learned--and I don't know when I learned this, but over the years I suppose I've picked it up--that the tricks of the trade (as my mother would say) are learning, first of all, where to get information; then using it. Turning it around so that you can use it to advance not necessarily only yourself, but other folks along with you. It doesn't matter how many times you advance what you think is your own child's avenue or open up their world, introduce them to different things--it doesn't matter how many times you do that. Every time you do that, you take other children along with you and other families. Maybe not a lot, but some.

It's a very grassroots essence, which a lot of people don't understand, that you have to be able to do that to grow, to grow bigger and bigger and bigger.

Drucker: The snowball rolling down the hill, it gets bigger and bigger and bigger.

Steneberg: That's absolutely correct, and that is what you really aim to do when you're doing true grassroots outreach. Now you've given me an idea. It has come to my brain, come forward in my brain. That's how I'm going to teach somebody now to do outreach. It came to my mind just as I was talking through here. That is how you do build the tools to do not what you desire, and you have to recognize this; you have to take responsibility also for what other folks come up with, in a sense. You have to understand that you're responsible for setting a seed, and it burst open and they picked up a lot of stuff, and look at all those other people now that you've indoctrinated because you set the seed. You see what I mean?

It's kind of a growing--that snow ball rolling down the hill, gathering more snow--that kind of thing, but I'm expressing it in a different way.

Drucker: Pollination.

Steneberg: Right, okay, pollination. It picks up other stuff as it goes along, and includes a lot more people. I can't emphasize enough this is what you have to do across the board, of all disabilities, across the board with regard to different people from different walks of life. Not just people like yourself. For instance, I'm white. Not just white people. You go to trainings. Whoever is there, they pick up--or you hope they pick up--something of what you've said.

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Steneberg: The other area of influence, I think, that I can speak to better is always being an advocate, in all kinds of meetings that I go to. Also, I live this kind of stuff every day, I suppose. It doesn't matter what I'm meeting about, where I'm meeting. Things come up during conversation that don't sound right. I think about them for a little while, and then I will bring them back up in meetings. Well, you know, you haven't really considered in this whole conversation such things as how do people get access to not only physical plant things but get access to people that they need to talk to, et cetera, et cetera, if they're not given the information in the beginning.

Information giving is so important. It must be given to everybody. People then pick it up and use it if they need to or want to. Other people, they think it's irrelevant to them, but it still rubs off sometimes. I've had people say to me, "Oh, I remember once when I was at a meeting you mentioned something about blah-blah-blah"--whatever it is. "I got thinking about that, and I have made a point now of making sure

that I address this issue more often." That's a plus. It really is, because it could be something that you and I might think is not important, but it at least stops people in midstream, and they think about something else and go off into a different plane or avenue. They can relate it back, usually, I believe, to disabled individuals, somebody who is incapacitated for whatever reason and not able to access something.

I think that's important. So those are just the little drop-off things which some people think are not important. I beg to differ. I think a lot of relative things are very important. It's not always obvious how relative they are to the subject matter, but they are sometimes very important. They just make people stop and think. I believe very strongly that never a day goes by--I know for a fact--that I don't learn something. Every single day I learn something I didn't know before, or something which knocks on my head and says, "Pay attention to this."

Well, that's my secret to gaining knowledge and getting information and being able to then regurgitate it [chuckles], as I say--it sounds revolting, but--when you need it. You'd be surprised at what things come to mind--not always at that instant when you need it--but quite often very close to the time when you're needing it. You suddenly wake up in the middle of the night, for instance, and think, "Oh, that's the solution to that problem." Then you go back to sleep. I sleep very well.

Women's Educational Equity Act of 1973 Project at Disability Rights Education and Defense Fund, 1979-1985

Drucker: Can I ask you about the Women's Educational Equity Act [WEEA] project? I know it was one of your first projects at DREDF when you worked there. Can you tell me about it?

Steneberg: Yes. Well, it was the very first project that I was employed to do at DREDF. I was going to get paid for it. I'd never been paid before by DREDF or by any nonprofit organization! So that's why it sticks in my mind a lot, I suppose. When it was proposed to me, I was very facetious about it. I mean, I just looked at the person that proposed this to me and said to them, "Oh, that's not the issue." Because the issue was around whether disabled girls were treated differently than disabled boys and vice versa.

I just sat there and thought to myself and then I said--I shouldn't have done this, but I did--"Oh, that's not the issue. That's the least of the issues with disabled kids. The issue really is whether they get to go to school in the first place! Whether they're able to participate with other kids that are not disabled, in a regular school. Those are the issues, not whether the girls are treated differently. You've got to get them in the door first, and there we can start sifting through that stuff."

Drucker: You didn't want to be part of a project that was first working just entirely on inclusion?

Steneberg: Right. I think I got a mind-set at that point, and I think I thought that these issues were not that relevant and that important. And then when I got into it, I knew they were important, but still didn't think they were top priority, should be my top priority at that point because my issue really was getting my daughter into school, and staying there. She would be in and out by that time of segregated settings into an integrated setting, back into the segregated setting. Back and forth two or three times. So, it really wasn't my top priority or issue.

But anyway, I worked on it, and I got into it. I mean, I was interested. There were a lot of things I really wanted to do, like traveling and seeing other folks around the country and meeting with them, usually in the same places--in Washington or in--not in their own environments, necessarily.

Drucker: Was the WEEA project only for the Richmond School?

Steneberg: No.

Drucker: Was it nationwide or statewide?

Steneberg: It's difficult to say it was nationwide. It was nationwide in the sense that all of the participants could come from anywhere within the nation, and did, and people that had projects all came together, particularly in Washington, at conferences, to go over what they had found and what they had done and how they had done it and curriculum, so it was educational for me.

Drucker: The same project was done in different cities all over the country?

Steneberg: Not exactly the same project, no. The disability projects were very absent, as usual. We had a few projects; there were only a very few--three or four, I think.

[tape interruption]

Steneberg: Well, the projects came together and we learned from each other, and that's how I learned a lot about a lot of these projects that didn't have any disability focus. The idea was to introduce them to disability: how would disabled people be able to be integrated into your project? That was the national focus in that sense, from our perspective.

Our project was comparing two very different school districts: one predominantly white and one predominantly black, in this area of whether girls were treated differently than boys in high school, between the ages of fourteen and twenty-two. Those age groups were chosen because that is the ideal age for doing transition and introducing the idea really strongly that you have to go out and work, and there has to be some accomplishment at the end of school.

To do that, you need then to go either to college or to a vocational education school or some other program which will train you to do what you want to do. That was the crux of the matter. It missed a very important component, as I see it, and that was independent living. It was felt that we didn't need to touch on that because other projects were doing that, not necessarily in the WEEA projects, but just generally speaking in school. That wasn't part of education; it was part of living.

Drucker: Were you actually tracking kids through a period of years to see how they progressed from high school through college and vocational school?

Steneberg: No, unfortunately we didn't do that. I happened to know some of the people who I could follow with and say, well, they haven't done anything or they've done very little. It's mainly to do with some decisions made by their parents or not by their parents, again. Or they would lose their benefits. Or the system itself keeping them more segregated, the living arrangements.

Drucker: What did you discover after you finished? Was it a year-long, two-year project?

Steneberg: Now I can't remember exactly. Yes, it was a two-year project. The other thing about this WEER project was you had to produce something at the end of it, in the form of publication. We more or less produced something; it was only camera-ready, and it was supposed to be the next book taking the place of No More Stares. Well, not taking place; you couldn't take the place of

No More Stares, but to carry on where No More Stares left off kind of thing, the next episode, if you want to say that. [Ann Cupolo Carrillo, No More Stares (Berkeley: Disability Rights Education and Defense Fund, 1982)].

That was the goal and the aim, but it never got produced. I mean, it never got printed, mainly because the project was ditched by Congress eventually, and then the money came to an end and there was nothing to do it with. So it sits on the shelf somewhere at DREDF or in the boxes [referring to DREDF historical archives, now in The Bancroft Library].

Drucker: What were your findings at the end?

Steneberg: The findings at the end were that yes, they were definitely treated very differently: belittled and given very much more menial jobs and opportunities to proceed. That's a summary; I could probably go into more detail, but basically that was what--they were only tracked or pushed into certain types of careers, and they were not very--I mean, cleaning toilets and janitorial stuff. It was not very inspiring. Unless they were obsessive about cleaning, which some students were, it didn't really amount to very much, unfortunately. The girls.

Boys, similarly, it's not that they achieved much more, but there were more boys in those age groups. I suppose the conclusion is nationally that boys are stronger and they live longer and this kind of thing. I don't know how true that is exactly, statistically, because I haven't looked recently. More studies have been done, I know.

It's very difficult to say, but in those days it was very obvious that they were definitely being treated differently.

Drucker: Tell me the difference between the two school districts, one that was white and one that was black.

Steneberg: Well, that goes into the dynamics of racial bigotry, and it also goes into the makeup of the school. For instance, as far as I could record, in the school districts, they were roughly about the same--the composition, the numbers of students--maybe a thousand here or there if there was a difference, but it wasn't that great. Which still amazes me. We have to remember this is some years ago, 1979-1985, somewhere in there. And the early eighties because we were still doing some. We had two shots at this. It was about a four-year project. There might have been a year in between. So I would say it was the early eighties, too, that we did some of this. Yes, I think that's right.

It was obvious to me that certain factors in the different school districts were very difficult to deal with. As far as I could record on the student count--and this is only students, however, that I diagnosed and identified in these counts, so it's always kind of said with tongue in cheek--I could only record eleven black students in the Mt. Diablo school district. It's an enormous school district. I couldn't really believe that number, and I still don't know that I do. I'm sure it's a lot more now, but it wasn't at that time.

Drucker: You mean, for the white school district.

Steneberg: Yes.

Drucker: There were only eleven black students, disabled black students involved in this project.

Steneberg: Yes. Well, not involved in this project--in that school district--that were actually identified and recorded with the State Department of Education as being black, whereas in the Richmond school district, which was the other school district, it was completely the opposite: there were very few white students identified. I mean, very few, in comparison with the overall numbers in the district.

For instance, in the learning handicapped category in the Richmond school district, there were very nearly three thousand students. Those are only identified, now. You have to realize these are not necessarily true numbers, because the ones that have been identified and given special education services, they're recognized, they're identified, they're counted, everything. But there are lots of students, however--and I keep saying this and nobody has ever listened to me about this issue--there are so many unidentified students.

I don't care what color they are. They're just there, and nobody ever gets to count them. They're in classes all over the place. I mean, you could walk into any, probably, class today in Richmond and find one or two learning disabled students, possibly. Even with very little expertise, you could say that. Say you're a substitute teacher, if you just go and do a little mental check, when you go every time and look and see--I mean, you don't need to be precise--just look: "That kid must have some kind of learning disability."

The Need for Teacher Training

Drucker: Has there every been training for teachers to recognize disabilities in students in school?

Steneberg: No. This is another big area which I pushed on for years and years and years, and I'm so thrilled now that teacher training is really being looked at very strongly, because it's the most important thing, I believe. The only way you're going to get any improvement in any of these schools is to get teachers who really are on the ball, really very sensitive to their students. Whether they have ten, twenty, thirty, or forty students, they've got to be able to be so aware that they can pick them up.

It's very difficult for people to do that, and certain people will be able to, and certain people won't be able to do it. The reason I think it's so important is that teachers have the most influence on the students. I don't care how old the students are. It's very important that their attitudes are brought across in a way which will help people understand that there are people with differences, and some of the differences happen to be disability.

I don't want it to stick out like black and white here, so that it can be so bigotried, etc. We need to be able to integrate them into everyday living. To do that, you have to first of all be able to recognize it and then you have to do something about it. That is where teachers can bring in the parents' attitudes. The parents get involved. That's what I think is one of the most overlooked things in teacher training.

Drucker: Because parents really look to the teacher for answers. Is that correct?

Steneberg: Yes, and the teachers don't have all the answers, and they can't know everything, and they can't recognize every learning disabled kid. But they have to be willing to put their hands up and say, "Well, we'll get the kid tested" or "I'll refer them, but you need to do it as well, mother, because if you do it, you've got much more clout than I have. I will back you up. I will do this, I will do that."

It's difficult for people to do, but that is the most important thing, I think, in teacher training. Lectures and conferences have been offered over the years. The majority of teachers--I'll just say all teachers--feel that that's the least important thing that they need to do. They don't need to

go to that life training--they have all these fancy different names for these trainings, which is basically special education--but they don't need to go to those because they know all that stuff.

Drucker: And they don't teach special ed.

Steneberg: They don't teach special ed, so they don't think it really relates to them. Whereas what they're really missing is the fact that in their own classes there are kids that need to be identified and helped. Whether it's one or twenty-two, it doesn't matter, the numbers. It's just that you've got to do something because otherwise those kids are never going to learn.

Participation in Demonstrations

Drucker: I wanted to ask you if you were involved in the sit-ins [at the federal building in San Francisco] in 1977, demonstrating for implementation of Section 504 [of the Rehabilitation Act].

Steneberg: I wasn't directly involved. I went over there and I demonstrated in the street and that kind of thing and witnessed a lot of that, but I didn't get shut in the building or anything. In those days, I suppose I was a bit leery of doing all that stuff. I didn't want to be arrested, and I didn't want to do all that. Because of my kids. I can't tell you the real reason why, but I think it's because I just felt, "Oh, God, look what's happened at home; I'll be locked in there." I don't think I realized how severe that was. I know somebody that was locked in there, with their kid. Everybody helped them change diapers and do all these things, but I can't.

Drucker: You started to change, though, because I've been with you to a few demonstrations. Have you always been willing to do whatever needs to be done, to do it?

Steneberg: Yes, as soon as I realized that this was really important stuff. I had good mentors. Judy Heumann took us in and was very sincere in the beginning and CIL was going to do our cases. Whether they really intended to or not, but they did. Julie Landau and Arlene Mayerson, for instance, they went to Washington, and Diane went with them, to make sure they did it, most times. They got the Bureau of Education for the Handicapped to at least listen to us and to say, "Well, this is preposterous" and to come down really hard on Richmond, and

held up the money. I mean, we are two parents, and if we don't have any other claim to fame, this is it. We got the State of California special education funding held up at the federal level until they got kids, supposedly, their occupational and physical therapy.

Of course, our kids did get therapy for a while during school. I think Chloe still gets it through CCS [California Children's Services, formally called Crippled Children's Services] from time to time. I don't know whether she gets any service now, but she's on maintenance--she gets equipment and stuff, or she was. Now she's over eighteen. I don't know what she's getting. I think it goes over to the Department of Rehab now.

The whole crux of the matter is we did get it--and to us, that was a very powerful statement for us. We felt like the big baddie guys because people made us feel that way; they intimidated us. Even the superintendent of public instruction in the State of California stood up and said, on national television, "Oh, it's just two parents in Richmond." Just two parents? A state this size? Thousands and thousands and thousands of children in special education? Give me a break! I mean, what's that say? He lied. He lied through his big fat--

Drucker: He was just saying, Oh, don't worry; it's just two parents who are against it? Except that you were able to close the school down. I mean, shut the money off.

Steneberg: Yes. The feds thought it was serious enough because they'd been around a bit--had done some reviews and had done some monitoring although not very much. So they held up, and it wasn't for very long. It was only for five or six weeks, or something.

That's when we really began to see that not only did parents have power, but if you really did something to these people, they start shaping up, because our kids got occupational and physical therapy more or less immediately after that. Richmond had to do it. But they had denied us fair hearings. They had done all kinds of things to us.

Drucker: Until the threat of legal action on your part?

Steneberg: Right. CIL was very instrumental in doing that. Well, it wasn't CIL at that time; it was the Disability Law Resource Center across the street, which was part of CIL, attached to CIL, the Center for Independent Living, in Berkeley, Judy

Heumann being the deputy. Every time we went there, she was there, sitting in on the meetings--just like she is now, when she has important things going on--not just in Washington around issues, but she goes and visits all these school districts all over the dog-gone country. She really does. Where there are these big pockets of problems along the lines of what they're trying to deal with. I mean, she's really Johnny-on-the-spot. She really is.

Drucker: Judy-on-the-spot.

Steneberg: Judy-on-the-spot, yes.

Start of California for Inclusive Schools [CIS]

Drucker: Tell me a little bit about CIS and how you helped start it.

Steneberg: Okay. CIS is a group of consultants to a Sacramento lobbyist. They advise the lobbyist on parent and educational issues. CIS has been a dream of mine for some while, since I was on the board of the National Parent Network on Disabilities, at the national level. It became very apparent to me very quickly that it was so important to have lobbyists--whether it was against the federal requirements in the Parent Training and Information [PTI] grants, or not. We weren't allowed to lobby. We're still not allowed to lobby directly, through PTI, and there are many gray areas.

So, it became very apparent to me that this is a political issue, whether we want to believe it or not, and we might just as well get educated and get in the arena of politics because it's going to smack you in the face every single time. It's going to be the biggest barrier. We've got to learn a way around it, through it, over it, whatever.

Drucker: Was that your idea?

Steneberg: That was the impetus for me to do this. My idea was to first of all try and indoctrinate the PTIs to say, "We need this," because if they weren't going to come along with it--and some people out of the PTIs weren't going to support it--then it wasn't going to work.

Drucker: The PTIs came out of IDEA, or were they in place before that?

Steneberg: No, PTIs are out of IDEA, special programs which are put in place to train parents or give parents information and resources.

Drucker: Is there money given from the feds for those organizations?

Steneberg: Oh, yes. They're all part of the IDEA. They come under the grant program, which is attached to--for training--anybody, actually. It doesn't have to be parents. But you can't get parent grants, of course, to do trainings for anybody else now. In those days universities were affiliated programs, and all of that, and some of the schools were, so it has changed over the years. But originally the idea was to train folks to help parents, as well. So that's where that comes from.

The other issue is, that's funded by the feds--sometimes not enough, of course, but they started many other experimental programs, and funded them. But when the money runs out, of course, they all die. So it was important to get people in those organizations on their own to be members and support a lobbying group, or a group, or a lobbyist.

That was the idea behind it. In doing that, I talked to many, many people--the PTIs, and all over the country--with regard to getting educated. I spent a lot of time in Washington, too, on my own time over the years, and sometimes it was in combination with PTI conferences and things.

II FIGHT FOR INCLUSION, LEAST RESTRICTIVE SCHOOL ENVIRONMENT, AND ENFORCEMENT OF EQUAL ACCESS

[Interview 3: March 19, 1999] ##

More Money to Segregate than Integrate

Drucker: First I want to start with the Stepping Stones¹ book, and ask you about something I read inside. I read a section about the Richmond district that said there was more money from the county to keep kids segregated than from the district to integrate them. Is this still going on?

Steneberg: Well, in the past, the county could get more money from the state Department of Education to educate the children from the districts in their county. That, I think, was how the county school system kind of started in special education. A lot of districts originally, before the days of the SELP, which was the Special Education Local Plan, model was used, contracted with the county they lived in to provide special education classes.

This is going back in history, in a way, because it's pre-master plan, which was a pilot project started in California. When was the article written in the book, do you remember?

Well, prior to that this new plan was put in place. It was a pilot project, and counties in California could choose to be in this plan or not. Up until that time, most school districts contracted with their county schools to educate disabled kids. It meant that disabled children had to go to one place within the county. Well, as you know, Contra Costa is a very large county, and so a lot of kids, like in Richmond,

¹ Sheryl Dicker, Stepping Stones: Successful Advocacy for Children (New York: Foundation for Child Development, 1990).

would be bussed all the way out to central county because the county school system was based more on central county. Contra Costa, being such a large county, it was a long way for kids to travel on buses.

You asked me where the money came from, why they got more money. The state opted to give more money to counties for special education classes, than it gave directly to school districts at that time.

Drucker: This is before IDEA?

Steneberg: Yes, yes. That has been the practice for some years. Kids would get segregated.

Drucker: Did some districts not do that?

Steneberg: Well, some school districts chose not to do that, but there were only originally seven school districts in California that wanted to be in this master plan because it promised them a lot more money to do special education classes, in an integrated way. It was a plan that for many counties was too big, especially a large county like Contra Costa County.

All the emphasis was put on bussing the kids to one point or another. That's how it came about that money was obtained for the special centers within each part of the county. There's a Richmond area, which is on this side of the hill and a little bit removed from the rest of the county, and it's lower socio-economically and there are a lot of black children and minority children in Richmond, whereas in the central county there weren't. That's where we did that study, the WEEA project, to look at the two systems, to understand how it was different and racially, too, not just what they wanted us to look at, which was gender, meaning the women's equity project.

[There were seven different SELPAs throughout California that applied for these grants using the same master plan model. The old master plan was a state plan, which was to be fully funded by the state. At the local (SELPA) level--Contra Costa county--the plan was to give money for special education kids. The problem was the regions were too large. For example, in Contra Costa county there were a total of 11,000 children in the Richmond School District, and 4,000 were special education students. The county did not get all of the money allocated because of funding caps. They created one central place where disabled kids were to go. Essentially segregated centers. Thus the busing issue and, as well, many kids just didn't attend because the centers were so far away.

There is a funding system in place that allows school districts special education funds based on the district's total population. This creates a funding cap for districts which they cannot exceed, even if the percentage of special needs children enrolled in their schools is higher than average. This funding system still exists today. --added by Pam Steneberg during editing]

Drucker: What was the most important thing that came out of all the work you've done in the Contra Costa district?

Steneberg: The Richmond Unified School District is now known as the West Contra Costa County school district. It has changed its name since the big scandal. The question was?

Drucker: The biggest gain--

Steneberg: The biggest gain. Well, I think the biggest gain was more apparent immediately--were two things. Children who were disabled not only needed services but they needed to be educated with their peers and nondisabled children. It really was the end of segregation as it had been known for disabled children in Contra Costa County. We didn't immediately stop advocating for children when we got the services.

We started this off quite innocently, trying to say that it was ridiculous that a public school system was giving our children less time in school than they were getting before, because now it was very much more evident to us, as parents, that they were falling more and more behind, and they were not catching up.

[The first place that Susan went to school was the Hilltop School. She went there from the time she was a year old until she was five years old. Then she went to the Richmond Unified School District. Wherever the county class was held, she went there through SELPAs. She went to Lake School--four or five different schools all over the district. --added by Pam Steneberg during editing]

Everybody had this idea, I think, that they would eventually catch up and be where "normal" children are. Well, it was obvious to us, because we're more realistic than some general public people, that our children would probably never catch up, so that's a misconception by itself. But that still doesn't mean that they shouldn't be educated to their full potential, which is exactly what the law maintains. That's when P.L. 142 [Public Law 94-142, or the Education for all

Handicapped Children Act], which was the original number of the law, was in place. It even said that children should be educated in the least restrictive environment, which is with their own nondisabled peers.

They should also be, I suppose, assisted. Well, actually, it said "benefit" from the special education under the law, but that is assumed to mean--and it is said in certain places--educated to their full potential. That was left very ambiguous and flexible because for some kids, like Susan, for instance, being educated to her maximum potential is possibly where she's at now. If she had been challenged earlier, I believe she probably could have gotten even more out of her education. But she wasn't challenged early enough, and it was mainly because she was kept in segregated settings.

For six hours a day she only saw other children who were severely disabled, some of whom didn't have any language, so of course she was not able to mimic them, which is the way she learns, because they didn't talk.

Drucker: You mentioned before, which wasn't on tape, that California was one of the states that did more than the other states when the IDEA was coming out. Were you working with different counties in the nation, or were you strictly working in California?

Steneberg: You're asking me two things. The law was put in place in 1975, and prior to that, I didn't know anything about any of this. I was learning it along the way. So it wasn't until about 1979 that I got full knowledge and was coming to grips with the fact that my child was not only being denied services, but that there were services which were essential for her if she were to even have any kind of independence, or be able to develop a life, or go to school, or do anything. But it took me time to learn all of that, having come from a completely different educational system, from a different country, and all that. You know, it just takes time.

But to answer the question more precisely, I was working in the beginning in the Richmond school district, just in that district, but I very quickly realized that it was a much bigger issue here in America because it's politics. Education is very politically charged. Even though I had no intention of getting so involved in the politics of the day, I couldn't avoid it.

In getting involved in that arena, to not only procure more funds but to get kids' rights brought to them and getting more involved with the disabled community, your fields broaden so much. You have to then start picking and choosing what

you're going to fight about. The political angle is so ugly at times, and is extremely ugly right now. I mean, there are mean people out there. It's no good saying there aren't. There are. Particularly members of Congress and people like that. Some are very sympathetic, but others are really into denying: "Why should those kids have special treatment?"

Politics in England's School System

Drucker: Was it as political in England? You were younger, but was it the same in England as far as a politically-charged issue in education?

Steneberg: It was and it wasn't. At times it was. But after the war, the British education system became much more socialized. It was a completely different approach. After national health was put in place, then people started really looking at the educational system and saying how archaic it was.

But disabled children in England were not really treated as equal, either. They still aren't. There are a lot of segregated schools there, some of which I've looked into from time to time. In England, it became very much more evident around the time of the thalidomide crisis, when drug therapy had produced children who were crippled, as they used to say. They were all segregated into special schools because they were political dears and they had to be taken care of. They didn't have arms and they didn't have legs and they walked around on their trunks and that kind of thing.

That, I think, brought it more into the political arena, there. Here, of course, the FDA [Food and Drug Administration] never approved the use of thalidomide, so it's not been so evident initially or as early on as it was in England.

The drug company that sold thalidomide lacked information. Its effects, in utero, was really brought forth from Australia originally. I was working for a drug company in England at that time, they set the alarm off that this was the cause of development of children without limbs.

But I want to just comment about it. It has kind of re-appeared in certain areas, and there have been many studies done around this issue of children born without limbs, around chemical infestation, like DDT and things like that, in the Central Valley, particularly here in California. I met a

gentleman who is doing whole studies on that. It's quite alarming.

And also in Bhopal India, after the American Cyanamid disaster [1984].

Fight for Regulations of the Individuals with Disabilities Education Act

Drucker: Can you talk about the formation of the Individuals with Disabilities Education Act [IDEA] and how parents worked together to bring that about?

Steneberg: Actually, this was in the works before my daughter started. Apparently, there were about eleven--in the early seventies--there were, total, about eleven different lawsuits throughout the country, which had been brought by parents to, well, I suppose they were trying to sue the federal government, but I'm not sure. They were definitely suing the state governments, because the parents felt that their children were being denied any education. They weren't actually asking for equality at that point; they were asking for their kids to be allowed to go to school. IDEA covers disabled children in the U.S. from birth to twenty-two years of age.

Drucker: Because these kids weren't even in school?

Steneberg: Right, they were not in school.

Drucker: And this was in the seventies?

Steneberg: I think it was before the early seventies. Yes, sixties, after the uprising in Berkeley and the whole civil rights movement really came into being, other people started looking at other issues after that. The issue for parents of disabled children was that their kids were being denied the right to go to school. If they weren't locked away in institutions, they were locked away in back rooms in their parents' houses, or such like things.

That was the beginning of motivating parents that they had to do something, to ask, "Why didn't their kids go to school like their brothers and sisters?" A lot of disabled children could learn, instead of being shut in institutions. If we look at folk in Europe, who are now speaking out more and more, particularly after the war--the German people know quite

a lot about this, and we've talked to many of them; some people have even come to DREDF over the years--have gotten themselves out of institutions.

A person that comes to mind--I can't remember her name--she came, and she was at the University of California for a short time, and graduated from there, from the Disabled Students' Program. She didn't have any arms at all. She had been locked in an institution in Germany. I think--she never actually came out and said it--but I think her parents had placed her there and then kind of abandoned her. I think she found her mother, who is now very elderly, after the war.

During the wartime, of course, Hitler exterminated disabled people. In fact, I've read two or three different books about that, and he exterminated more disabled and crippled people than he did Jews. It is in the Holocaust Museum. There's one window which is--and I remember that, too, when I went there, and I've been there two or three times--it's kind of interesting; the numbers were so large. And he did awful experiments on people.

Early Segregation within the Independent Living Movement

Drucker: And who was responsible for this first wave of the disability movement?

Steneberg: Centers for independent living were the first creation. It was really the students out of the civil rights' times who rose up in Berkeley and tried to go to university--Ed Roberts and people like that--who created the Center for Independent Living, so they could speak out and join their own lives together.

But, you see, it was a very strange time at the end of that, and it was very closed because they were a bit segregated in their own thinking at that point. Most of the people I met in the beginning didn't really accept us parents as being part of the movement. They wanted to hold us out.

Drucker: Why?

Steneberg: It took me a long time to discover this feeling that I had. They wanted to listen to us because they were interested, but they also didn't want to let us in to "their" movement. I mean, it was like they had ownership of it. For a long time--

and Diane and I discussed it a lot--we felt like outsiders. We discovered after some time it was because they were angry, most of them, at their own parents because they had kept them in these very closed environments, the segregated schools, thinking they were doing the best for them. I mean, it was just part of the times.

Then they saw us coming, and they saw us as being the same as their parents. You know, we wanted to protect our kids, and we wanted to do things for them instead of making them more independent, and we did want to put them in regular schools. So we felt very much outsiders in the beginning. It was a long time before some of the disabled people began to accept us.

One of the first people that did accept us was Judy Heumann. She felt that yes, we did have a place. Really and truly, she was very close to her own mother, and her own mother had not really kept her segregated or separate. Her own mother had just taken her along to the public school and said, "My daughter is coming here." Judy knew that. But she had to fight all the way. I mean, if you listen to her story, which I'm sure you probably have from time to time, you'll know that she had bucked the system because it was the system that's archaic, and it still is. It's archaic in its thinking. It's not progressive and not fast enough.

Most people were brought up in a time when you did send kids that were that different away to the hospital or institution. It's just a change of the times, really.

Drucker: Back to the eleven lawsuits. How did that start?

Steneberg: Parents started talking to each other, and they starting saying, "We should go further with this. Why are we spending all this money? Our kids have rights, as citizens. They're born in this country." So they started talking to the congressional people. Congress, in its infinite wisdom, picked up on it. In fact, Judy Heumann helped write a lot of the original law. She had been a teacher in New York, and she had the experience of being--after the polio epidemic--she had the experience of being kept out of school.

Drucker: She had a lot in common with them.

Steneberg: Yes. Well, it was a democratic congressperson that really started it off, coming together and thinking, well, we should write a law around this issue. I can't remember the name. He

(Harrison Williams) was from Connecticut. But anyway, Judy worked for him, and that's when this law was crafted.

Drucker: Were you interested in going to Washington?

Steneberg: Well, I didn't want to do that. We got in on the gain because our kids were denied the right to be in school more than just [...]. What was crazy for us--Diane and myself, not that we knew anything about it in those days--was that they had been in a development center where they went to school--or they went to the development center segregated for six hours a day--and then when they went into the public school system (also segregated), they were told they could be there in the morning, two and a half hours. Yet they needed all this extra therapy, like occupational and physical therapy, and these related services, which took up all the time that they were there.

[When Susan went to the public school system, the day was shortened for her and not for everybody else. The school day was shortened from six hours to two and a half hours, thus cutting her time being integrated with her peers which was very detrimental to her reaching her full potential. --added by Pam Steneberg during editing]

So the disabled children didn't learn anything--anything! They didn't get any education. Teachers were just doing physical therapy, sitting them up and trying to get them to talk and all this early infant stuff.

Drucker: So you and many others were really responsible for disabled children being educated in the true sense of the word, I mean, really educated. That's a very big thing. Just think of the millions of children you've influenced. But you had to get the law passed.

Steneberg: The [IDEA] law was already passed in '75. But it was in that stage where it was in limbo. [President Richard M.] Nixon wouldn't sign it. It wasn't till--eventually, [President Gerald] Ford signed it. It was during that interim period when the Watergate thing was going on. That was more important--let's face it--than dealing with what they thought were a few disabled children.

See, the thing about this population, the severely handicapped, it's only a very small minority. I know it sounds, and we make it sound as if it's this great big bunch. It is a lot of kids across the country, but it's also only the minority of the amount of kids in schools.

Attempts to Deregulate

Drucker: So you were really fighting for the implentation regulations for the Education of All Handicapped Children Act to be put in place.

Steneberg: Yes. The regulations were not in place.

Drucker: What year was that?

Steneberg: That was in the early eighties.

Drucker: Tell me about that.

Steneberg: Well, we organized parents on the West Coast to all congregate --from Hawaii and Alaska--to congregate in Los Angeles, because it was the only area where they had a hearing. That's what we tried--CIL and the folks there--tried to motivate people to go to L.A. to give testimony and to oppose what [Health, Education and Welfare Secretary Joseph] Califano was trying to do in his whole regime. It was when?

Drucker: Seventy-seven.

Steneberg: Seventy-seven, right. It was around the same time. It was kind of like being pulled this way and that way. The disabled community wanted us in, because we swelled their numbers. We wanted our issue dealt with, which was dealing with this Education for all Handicapped Children Act. We had already gotten into trouble with the California Department of Education around Richmond not providing them early services. Then the state kind of pooh-poohed it, and said we're just two parents from Richmond, who fortunately had managed by this time to link up with CIL and the law center.

Drucker: What happened in L.A.?

Steneberg: We had been to Washington and done the whole thing around our kids. We went to L.A. when they tried to deregulate it, and we joined with a lot of people who came not only from the L.A. area but from all of these other western states. It wasn't a lot in the sense of how many kids there are. It was just handfuls of parents, people from different places.

But we here in San Francisco, mainly from Berkeley, managed to get quite a few people to go down there. There were many parents and children.

Drucker: What happened when you went down?

Steneberg: We gave testimony. We got it all together, and we gave testimony. Arlene gave testimony. A lot of people, like Corbett O'Toole and all those people were on the same bandwagon. We all gave testimony. We made big nuisances of ourselves, of course.

Drucker: Was the hearing publicized?

Steneberg: Not very well, no. That was their idea. They thought they were going to sneak in and just deregulate it, and that would be it.

Drucker: And then what happened?

Steneberg: Well, we managed to get them to stop and think. Congress decided that they weren't going to touch it, so then they left it alone.

Drucker: So, you succeeded?

Steneberg: Yes, we succeeded. School districts, of course, hated it. That's when we became proficient--more proficient--in learning not only what the law really said, but also trying to implement it. That's always been difficult, because a lot of parents are not that well educated, and they can't sometimes read the silly thing. That's when the whole area of training started, training parents on rights, and going around to parent groups and school districts. What we're still doing, actually. Giving information out.

Academic Learning or Education?

Drucker: This leads perfectly into my next question. Can you remember any really interesting moments in the early days, either protests or hearings or moments, when you were forced to change how you looked at something, or when you made others see things differently?

Steneberg: Made others see things differently?

Drucker: Either parents, or Congress. Do you have any specific moments or details in your memory bank of experiences over the last thirty years? Do you remember specifically any protests or hearings?

Steneberg: I've given testimony at many hearings, but the one I think that still stands out in my mind the most was when we were giving testimony before George Miller's staff in our own county, our own politicians, out in central county. He held a hearing. We had our stories together, of course, as parents. But it was a bit astonishing that the school district, the one that we live in, came out in full force and really tried to use their own agenda, which for Richmond was more or less sad.

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Steneberg: "This will never work." "It's going to cost too much money." "Why do those children need to be educated for, anyway? They're not of any use." I mean, it was the old-fashioned idea that disabled kids were not worth spending money on in this way, trying to educate them. As we all know, they're disabled --perhaps only physically--but they're perfectly able to learn and be educated.

The whole emphasis also is that somehow people--to me anyway--in this country have the idea, or had the idea, and I think a lot of them still do, that you have to be academically inclined, and go on to universities, and do great things to be educated. That has not ever been my impression of what education really means. For my daughter, who has an individual educational plan and always had, her education has been really basic learning: how to be more independent and functioning every day just in the real world. Quite honestly, she does not read. She can recognize words. She does not do math. And she does not do sophisticated educational academic work in any remote way. But she's able to live in her own apartment now, in a more independent way. She knows how to do certain functions which have been taught her by repetition, and by what she observes. It's nothing to do with being academically inclined.

Drucker: Do you think that the district was so against you because they saw that disabled kids were never going to be academically excellent?

Steneberg: That's correct. It didn't really matter to them, I suppose, that a lot of children who were disabled would grow up to be--what shall I say?--cooks and other things in life. They can do a lot of jobs. I've seen quite severely mentally disabled people working in warehouses, doing all the menial jobs that nobody else wants to do in this day and age, which is very evident. But they're quite satisfied, and they're employable.

Drucker: So this, the way the school district representatives were acting, did that really just put more fuel into your fire, so to speak?

Steneberg: Yes, absolutely. It was very infuriating to hear the other side, because they were never truthful with it. They were never truthful to your face. They obviously fostered a lot of resentment and negativity, actually. We were a pain in the neck. I mean, I was a pain in the neck. I know I was. I was very angry at times. In fact, my other daughter often tells a story about how one time, when I went to give testimony before the state Department of Ed--the Special Ed Commission, I think it was--around an issue--I can't remember what the issue was--I really got very angry, and I was banging on the podium, REALLY LOUD! [Chuckles]

People in the audience were kind of [laughs]--even looking and listening--and it was kind of like this whole, "Well, what's she getting so mad about? It's just a bunch of disabled kids," kind of attitude. One guy, who was behind my daughter, my teenage daughter at that time, was saying, "Gosh, that woman's really mad, isn't she? She should be a lawyer!" Which has obviously stuck in my daughter's head because she's now nearly a lawyer [laughs].

Drucker: So what was the outcome of that particular hearing that you just talked about?

Steneberg: Oh, I know it was around integration. The least restrictive environment has always been a sore point for administrators from the old school, because they really don't believe that kids should be able to participate in regular classes. There's still a lot around in many of the school districts. It's amazing, actually.

I always have to step back and think, when I go out of state or when I go to Washington or whatever--I mean, you hear all these stories from other parts of the country--I really have to think that I've been very lucky in some ways because I live in an area which is much more open-minded and flexible around people who are different. Whereas, in some of the Midwestern parts of the country, they really aren't. There are people still having the same horrendous things said to them that were said to us some time ago. So it's very spasmodic throughout the country about how integration--mainstreaming, they used to call it--has advanced.

It's still not there. We've still got to work on it. We're doing it every day. In fact, we've only just established

our own lobbyist in Sacramento to try and integrate much more into the regular education system.

Effects of Americans with Disabilities Act of 1990 [ADA]

Drucker: How has the signing of the Americans with Disabilities Act changed people's attitudes toward children with disabilities, if it has at all?

Steneberg: Well, I don't know if the ADA has had so much--it has indirectly--changed the lives of children, because the school districts are not there yet. I hate to say this: most school districts are not even in the arena of letting kids into regular schools. The ones that do, that have what they call integration programs--and Richmond early on was better than it is now. I mean, they've suddenly woken up to the fact that, "Oh, we've got to plan this." I mean, it's just, like, unbelievable.

Each different generation that comes along has to be re-educated.

Drucker: So the law hasn't really integrated kids into regular school settings.

Steneberg: Well, that's not true. It integrated some kids, but it's very spasmodic all over the state, even in California. Some districts are further along with their integration plans and programs than others. That has made it very unequal again.

Drucker: But the law has been in place for the last twenty-five years. In twenty-five years you'd think something would happen, no?

Steneberg: Things are very slow to progress, I mean, politically, for all different reasons. It takes ages to convert districts. The main problem, as I see it, is not only teacher training. But teacher training is very important, because teachers have not been prepared, when they come out of university, to deal with this population. It's a lack of education way back at that level.

The people who are coming out of teacher training now are much more open-minded, but they don't necessarily have the skills and tools to do it in the way that it should be done. They have too large classes. The reason that I decided--in my little arena where I was--that I would join the regular

education push to reduce class size was selfish, in a way, because I could see that that would assist handicapped integration. The smaller the class, the better the attention that the individual disabled student would get. And that's what they need, most of them.

Drucker: You mean reducing class size for regular education?

Steneberg: Yes, regular education. Then, there's no excuse for teachers not taking disabled students, because they would say, "Well, I can't do it with forty in my class," which really and truly was true; they couldn't. They needed assistance. But the thing is that it needed to happen at that level. Now they've started to reduce class size. But it's still too slow. Most classes are still too big, in big districts.

I've just thought of something else. The other problem is the unions. The union movement has a place, but they are very resistant to doing integration, the education unions, teachers unions. They now see it as being an issue about money, but originally it was just, "Oh, no, they couldn't have those kids in their classes because the contract didn't say they could." It's that kind of union issue. Handicapped children were not contractually in the contract, they were separate. So that's what made it a separate place, a separate everything, whereas it wasn't as integrated as it should be.

Now we're saying very strongly that special education is not a place. It's just services that you render to children who need extra help.

Heroic Acts

Drucker: What was the single or double or triple most heroic act in your political career? In other words, what took the most bravery?

Steneberg: I suppose getting up and testifying before Congress was one thing. In the beginning, I was very nervous to get up and give testimony. I didn't think I knew what I was talking about. But it didn't take me very long to get over that one, because I realized, as I was talking to these people, they didn't know what they were talking about [laughs]. Not that that's very nice to say, but it's true.

The last time that I really felt heroic was when the new Congress took over eight years ago. I spent nearly a whole

month in Washington. For three months, I went back for a week, for three months, when the new Congress was being formed, listening to school administrators from fairly large districts around the country trying to overturn the special education law, just blankly saying, "It's too costly. We're not going to do it. Dah-dah-dah-dah-dah."

It was very frightening. It still is. There's a lot of congressional people who don't understand these issues at all around disability, let alone the issue about kids going to school. So it has been--I feel, quite honestly, it has been done very backwards. It has come from the grass roots.

It should have trickled--this trickle-down theory that you hear from government and from people like President [George] Bush and all these people--but they don't know what they're talking about. Trickling down! I mean, they're trickling down only economical, financial, kind of jargon and not giving them enough money to do what needs to be done.

Another terrifying issue was--since you asked me that question--was when I really felt that I was being a rebel. That was in the beginning, when we opposed a Department of Ed person for the first time; also trying to stand up against this antiquated system that's still present in California called CCS, California Children's Services, it's now called. But it was originally called Crippled Children's Services. It's trying to stand up against them. My daughter was in need of occupational, physical therapy. She never did get physical therapy, but she did manage to get occupational therapy.

That was our first issue, that we would continue to receive the same services that the children had in the development center because it was obviously helping them, and they needed to continue. They were not willing to give it to them. Everything was separate again. It was this kind of separate system that they had in place. They [the Department of Education] never ever got a partnership agreement with the Department of Health.

The Department of Education didn't want this issue. They wanted to give it to the Health Department; the Health Department didn't want it. They said it was Education's responsibility. In the beginning, the state Department of Ed tried to ignore it. That's what brought it to the head, that related services is an educational need for some children. They weren't willing to provide that.

Trying to get those two agencies to at least talk to each other was a biggie, and it wasn't done until it was fought through regulations. We really had to get--especially the Department of Education--to get the two entities in one room and say, "Look, you've got to do this." The responsibility, as the interpretation of the law says it, remains with the education department.

That was a whole terrifying experience, because it showed how the politics didn't always work, that people didn't really understand the issues. We even have a law here which is a fallout from this whole thing here in California. Some folks went into their legislative person's office--it happens to be Willie Brown--and wanted to get mental health services--to do more or less the same thing to help children who needed mental health services in schools around behavioral programs and all that, which has now become a discipline issue, together, in one room.

Brown, in his naivete, his office, I should say, not understanding the issue, over a quick summer produced this law in California which went whooshing through the committees, without anybody really being aware of it, including being allowed to give input, except a few folks. Then some other good guy came along and said, "Well, let's put all related services in this law," which then fouled up everybody else's issues. We had just gotten California Chidrens Services in the arena, and now there was this new law, 3632 [California Government Code Section 7570-7579.2], in California, which said all related service should be provided under the law.

They were not about to [provide these services because there was a practice of segregation]. They wanted to completely segregate people in institutions.

That's the impact the political arena has to play into all of this. That wasn't thought through very well in the beginning, with the states. It's only now getting better. The Department of Education is actually clarifying things in its new latest regulations in 1999. Well, actually, it's 1997 the IDEA was passed, but the regulations now, two years later, are just in our hands right now. It's a federal law.

It does clarify a lot of issues around a lot of things, actually, but they should have been there in the first place.

Keys to the Future: Education, Change and Enforcement

Drucker: What do you feel about the different kinds of organizing that you did, the different strategies of organizing, such as litigation, lobbying, community organizing, the media, unions, and partnerships with officials inside government? Which do you feel are the most important, and which have you used the most in your political career?

Steneberg: I suppose the most important is first of all, always, educating, educating, educating. Educating people. It doesn't matter where they are--in which agency, in government, the congressperson, whoever--just educating them about the day-to-day life of disabled children, particularly in families, and in our own communities. Then everything that goes on from there is just educating, educating, educating.

Drucker: What do you see for the movement in the future, and what laws have to be enacted or enforced for the changes that need to take place to be made?

Steneberg: That's a very big question. The future holds, should hold, the same for disabled children [as for nondisabled children], the same opportunities, the same choices for all disabled children in school and not in school. See, the thing is that even in certain areas there are a lot of children that are still not in school. Never mind about being in special education. They're not there because the information has not been given to their parents or they're immigrants and they don't know that their kids have a right to be in school.

Constantly giving out information is key, because, I'm sorry, but school districts do not part with any information if they don't have to. It has to be dragged out of them. All the school districts--particularly in California, which I cannot understand the system, even now, today--have their own policies, and a lot of them are totally discriminatory.

People also just misinterpret things, like every summer we have issues around letting disabled individuals walk across the stage to receive their diploma. Every single summer. Or just before graduation.

Drucker: Why?

Steneberg: Don't ask me. I don't understand half of them. They're just very discriminatory and old-fashioned or whatever you want to say. So I feel that the wave of the future is that people have

got to accept change. It's very difficult to change your ways and be forward thinking and have visions and let other people have visions. I mean, if somebody who's in a wheelchair says to you, in the classroom where you're teaching, that they want to be a fireman, and you know in your own heart that they're never likely to be a fireman, what do you say to them?

You have to educate them to expect that they will be limited--if they can't walk, or whatever their disability is--that they will always be somewhat limited, but that needs to go on, the education of the individual, as well as society. It's no good just educating the individual and saying, "Look, you can't possibly be a fireman. You can't walk." But people have dreams, and they have to be allowed to get through their dreams and begin to realize that they have limitations, too.

That's a very hard thing for disabled people to do. I see it daily, where people are really denying that they have this disability. I mean, I've done it myself, so it's kind of like I'm a disabled woman. I've never wanted to admit that I couldn't do anything that anybody else could do.

Drucker: The individual and society at large.

Steneberg: Yes. The individuals themselves have to be educated, too.

Drucker: Legally, of course, there are not five hundred DREDF's suing school districts that aren't complying, so there's nothing to make them really comply. Is that right?

Steneberg: That's not quite true. School districts are supposed to understand the law, and they're supposed to work within the law, like everybody in the country. Just people that break the law and consistently keep breaking the law, even when they're told, and don't try to do anything to change the policies or whatever the restriction is, but that's not the only thing. People lie.

I've had administrators--in fact, even just yesterday somebody said to me, "The administrator said, 'We have a policy.'" When they started to look into that, they didn't have a policy. In fact, the office said to the person when they went to get the policy, "Oh, we don't have a policy on that." So where did that administrator get that idea from that their policy was against it? That was him saying that.

I mean, they're racists in the sense that it's the same as civil rights issues around race. They don't want "those people," and they say it to you constantly--parents hear it--

"We don't want those people in our classrooms." Then they try to make parents feel guilty and tell them things like, "He won't be protected there. He's not safe."

Drucker: It's very much about ignorance. People still don't understand what it is like to be disabled or to have a child who's disabled. It's still totally ignorant.

Steneberg: Yes, it is, actually.

Drucker: Is there anything else you want to say before we finish?

Steneberg: No, I don't think so. I just think we need to be very much more visible, and we need to be out on the streets and pounding at the door. Not only implement the law but enforce it. Enforcement is another issue which is very weak. We have all these wonderful laws, but nobody ever enforces them, most of the time.

Drucker: How can we enforce them?

Steneberg: The restrictions need to stay in place, the regulations need to stay in place, and I'm afraid the state departments of education and the federal Department of Education need to be a lot tougher. They really do. They need to start taking local school districts--if they want local autonomy, which they keep on talking about--to court and join with parents. I mean, it's not this one-sided business. That's where parents won't trust administrators because they don't see them as doing the right things by their kids.

Drucker: Thank you very much.

Steneberg: You're welcome.

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